Family Matters

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Introduction

Chronic Fatigue Syndrome (CFS) and fibromyalgia (FM) are family matters. One person may be the ill, but everyone in the family is affected. Both conditions

- Put marriage under serious strain
- Intensify normal stresses such as money, sex, parenting and careers
- Create new stresses because of the limitations imposed on the person who is ill
- Bring uncertainty about the future
- Trigger anger, fear, resentment, grief, guilt and depression

Even though CFS and fibromyalgia create great challenges, there are many strategies that can reduce the stresses and improve quality of life, both for the person who is ill and for other members of the family.

This text addresses three questions:

- What is important to know about these two conditions?
- What adjustments can the family make to live better with long-term illness?
- How can you help your loved one and also take care of yourself?
Chapter 1: Roadmap for CFS and Fibromyalgia

When someone you know first developed symptoms of Chronic Fatigue Syndrome (CFS) or fibromyalgia (FM), you and she may have thought the problem was a lingering short-term illness. But at some point you realized that you and your loved one had entered a new realm: the world of chronic illness. Instead of resuming familiar patterns and routines, you and she were faced with the prospect of adjusting to a different life.

Your challenges may have included some, many or all of the following:

- Extra household tasks
- Financial strain
- Caregiving responsibilities
- Strained relationships
- Worry and uncertainty about the future
- Uncertainty and a sense of helplessness about how to help
- Resentment and frustration
- Sadness and depression
- Increased stress
- Sexual difficulties
- Loss of companionship
- Strained communication
- Less socializing
- Extra parenting responsibilities

The course will discuss these challenges and how to respond to them. We begin with a roadmap of the world of CFS (also known as CFIDS and ME) and fibromyalgia, focused on five characteristics of the conditions.

1) CFS and FM Are Real and Common

Chronic Fatigue Syndrome and fibromyalgia are now widely recognized as real illnesses, not psychological problems. Diagnostic criteria have been established for both and a diagnosis of either condition qualifies a person in the US to receive disability payments.

Since there are no diagnostic tests or any proven physical marker for either condition, diagnosis is made through a combination of excluding other conditions and identifying a distinctive pattern of symptoms.

A diagnosis of either Chronic Fatigue Syndrome or fibromyalgia does not rule out other illnesses. In fact, both CFS and FM are commonly found together with other medical conditions. (See the next section for more detail.)
Both CFS and fibromyalgia are common. Research suggests that there are probably 800,000 or more adults with CFS in the United States; children and adolescents also experience CFS. About two thirds of people with CFS are women. Estimates of the prevalence of fibromyalgia vary, but there are probably at least five million people in the United State with FM. Studies suggest that more than 90% are women.

2) CFS and FM Are Serious and Long-Term

Both conditions are characterized by the presence of several to many symptoms. Treatment usually focuses on four:

- Fatigue
- Pain
- Unrefreshing sleep
- Cognitive problems (“brain fog” or “fibro fog”)

Fatigue:
Fatigue is experienced as deep exhaustion that can be caused by low levels of activity or for no apparent reason. Often, the effects of activity are disproportional to the energy expended and last far longer than it would in a healthy person. This is called Post-Exertional Malaise or PEM.

Pain:
Pain is generally felt all over the body. It may be accompanied by tingling and burning or numbness in the hands, arms, feet, legs or face. may be experienced in the joints or, more commonly, as a non-specific pain felt over the whole body.

Sleep:
People may have trouble falling asleep or may wake up frequently. In most cases, sleep is not experienced as restorative or refreshing.

Cognitive Difficulties:
These include confusion, difficulty concentrating, fumbling for words and lapses in short-term memory.

Other common symptoms in CFS include headaches, low-grade fevers, sore throat, tender lymph nodes, anxiety and depression, ringing in the ears, dizziness, abdominal pain (gas, bloating, periods of diarrhea and/or constipation), allergies and rashes, sensitivity to light and sound, abnormal temperature sensations such as chills or night sweats, weight changes and intolerance of alcohol. Emotional problems such as depression, anxiety, irritability and grief, are also common.

Many other symptoms may accompany fibromyalgia, creating additional discomfort and frustration. Common additional symptoms include tension or migraine headaches, strong
emotions such as depression and anxiety, jaw pain, ringing in the ears, dizziness, rashes, sensitivity to light, sounds, smells and temperature, and dry eyes or dry mouth.

Managing symptoms is complicated by the fact that people with CFS and fibromyalgia often have one or more additional medical problems. A majority of people initially diagnosed with CFS or fibromyalgia are later diagnosed with the other as well. In addition, both conditions are often accompanied by additional medical issues, such as the following:

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

Although CFS and FM appear in a wide range of severities, the average person in our program rates herself at about 25% of normal. This means that she has had her activity level reduced by 75%.

**Treatment**

Because there is so far no cure for either CFS or fibromyalgia, treatment focuses on controlling symptoms and improving quality of life. Approaches include medications, alternative treatments and self-help measures. Medications are often used for improving sleep and controlling pain, though their effectiveness varies greatly from patient to patient. Since no medication is consistently effective, treatment usually consists of a process of trial and error to find what works for an individual patient.

How a person with CFS and FM lives and the actions of those around them have a big effect. Because symptoms are intensified by factors such as too much activity, stress and poor sleep, they can be reduced by adjusting activity level, reducing stress and improving sleep. Helping your loved one adapt to the limits imposed by CFS and/or FM may be the biggest help you can offer.
Prognosis

The outcome for CFS and fibromyalgia varies from person to person, but for most people, the conditions are long-term. Among those with CFS, a small number recover. Another, larger group achieves some improvement, but less than full recovery. The total of these two groups is probably about half of CFS patients. Unfortunately, others remain quite ill, while a few worsen over time.

The prognosis for people with fibromyalgia is somewhat better. While FM is, for most people, a long-term condition, it is neither progressive nor fatal. A small number of patients experience a spontaneous recovery. Many FM patients experience notable improvement. In fact, improvement is probably the most common outcome for fibromyalgia, experienced by half to two thirds or so of patients.

(For more on diagnosis, symptoms, treatment options, and prognosis, see the articles “About Chronic Fatigue Syndrome” and “About Fibromyalgia” in the Library section of our website: www.cfiddselfhelp.org.)

3) CFS and FM Have Comprehensive Effects

CFS and fibromyalgia touch every aspect of life: patients’ ability to work, relationships, emotions, dreams for the future and their sense of who they are. Chronic illness is a challenge to manage because its effects are so comprehensive. Living with CFS or fibromyalgia means much more than managing symptoms.
Complicating the challenge, there is an interaction between illness and other parts of life. Illness restricts a patient’s life in many ways, but, in turn, is affected by other areas of life. (See diagram.) For example, illness puts limits on a person’s activity level (arrow pointing from CFS/FM to Activity). But, if patients do more than their bodies can tolerate, the overactivity causes a higher level of symptoms (arrow pointing in).

The same pattern of reciprocal effects is true for other elements as well, for example the relation between illness and stress. Long-term illness often increases stress because of things like ongoing symptoms, financial pressure and uncertainty. At the same time, people with CFS and FM are very stress sensitive, so that stress creates a disproportionate intensification of symptoms.

In summary, CFS and fibromyalgia have comprehensive effects, touching many parts of a patient’s life. They are much more than simple medical problems. A plan for managing them has to address all its effects, not just symptoms.

4) Each Person’s Situation is Unique

The situations of people with CFS and fibromyalgia are vary widely in several different ways. In terms of severity, some people have relatively mild cases, while others may be bedridden. Most people are in between. Most people taking our self-help class rate themselves as functioning between about 15% of normal and 35%, but some with severe cases are bedbound, while others work part time and a few full time.

Also, there are many different patterns of symptoms. For some people, fatigue may be the most bothersome symptom, while for others it is pain. Adding to the complexity, an individual’s illness may vary over time. Some symptoms may disappear, only to be replaced by new ones. Some people may have a relatively stable course, while others may fluctuate between times of severe symptoms and times of remission. The bottom line: each person's illness is different.

The likelihood that a person will improve is also shaped by the person’s circumstances. This includes stage in life, finances, caregiving responsibilities, and sources of support. Two additional factors affecting the course of illness are coping skills and attitude, both of which can be changed.

Research has shown that people can learn effective coping skills for managing long-term illness, either on their own or through self-help classes. 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. People with this attitude combine recognition that life has changed with a conviction that they can find ways to improve.
5) CFS and FM Are Affected by the Patient’s and Family’s Response

How CFS and fibromyalgia patients conduct their lives has a major impact on their symptoms and quality of life, often a larger effect than medical treatments. As prominent CFS/FM physician Charles Lapp says, “There are limits to what your doctor can do.” The key to recovery with these conditions, he says, “is acceptance of the illness and adaptation to it by means of lifestyle changes, for which medical treatment is no substitute.”

Living well with CFS or FM requires a level of management similar to that for other serious, long-term conditions, such as diabetes: major, long-term lifestyle changes to control the illness.

Those around the patient play an important role, too. Your actions and attitudes will have an significant effect on your loved one’s symptoms. For example, by helping her adjust to her limits and by working to lessen family stress, you contribute to your loved one’s well being.

You may not be able to change the fact that your loved one has CFS or fibromyalgia, but you and she can learn new and more effective ways to deal with the condition. Those who do best living with chronic conditions often believe in their ability to exercise some control over their illness. These people do not deny they are sick or hold unrealistic hopes for recovery, but they have confidence that they can find things to make their lives better.

In summary, good coping skills --both hers and yours-- can make a significant difference to your loved one's condition and to your family's quality of life.
Chapter 2: Family Adjustments

Chronic Fatigue Syndrome and fibromyalgia bring dramatic and far reaching changes, not only to the person who is ill but also to those around her. Predictability is replaced with uncertainty, stress is increased, emotions are intensified, and many practical aspects of daily life are altered. And, as mentioned in chapter 1, much of the burden may fall on you as a spouse, other family member or friend.

This chapter focuses on six areas of adaptation.

1) Household Tasks

CFS and fibromyalgia usually lead to a redistribution of household tasks such as shopping, cooking, cleaning, laundry, bill paying and child care. For those things the person with CFS or FM can't do or can't do in the same way as before, there are two main options: reassigning and simplifying.

*Reassigning* means finding someone else to do part or all of a task that the person who is ill used to do. Probably the most common solution is for the spouse to take over some or even many of the duties formerly done by the person who is ill. But there are other solutions as well.

If there are children living at home, they may contribute in various ways, such as by keeping their rooms clean, helping with meal preparation and doing their own laundry. If adult children live nearby, they may offer practical help as well. Another solution is to pay for help, for example by hiring a cleaning service on an occasional or regular basis.

*Simplifying* means continuing to do something, but in a less elaborate or complete way. For example, people may clean house less often or cook less complicated meals. Some people simplify by downsizing their home, for example, by moving from a house to a condominium.

2) Financial Adjustments

The financial effects of CFS and FM vary greatly. Some families make no changes to their finances or only minor adjustments. This may occur if the person who is ill was not employed when she or he became ill or was at or near retirement. Some people are able to arrange an early retirement with a slightly reduced pension. (A few people who continued working while their symptoms worsened have told us that they wished they had evaluated their financial situation earlier and retired sooner.)
For other families, however, illness creates moderate to severe financial strain. For some, family income is cut drastically. If the patient is unable to work, family income may be reduced by half or more. A successful application for disability payments can reduce the deficit. (About one third to 40% of the people who take our introductory self-help course report receiving disability.)

Families in our program have used several additional strategies in response to financial stress. In some cases, a healthy family member changes jobs to get work at higher pay or with better benefits. Some families report that they established financial discipline by strict budgeting and a reduction in spending. Others have moved to smaller, less costly homes, a strategy which can reduce both expenses and household tasks.

3) Social Adaptations

Because people with CFS and fibromyalgia have significantly less energy than before, they often reduce the time they spend with others, creating a loss of companionship both for themselves and for those around them. Factors such as energy limitations and sensitivity to sensory input (noise, light and movement) may force a reduction in the length, the type or the form of socializing.

People with CFS and FM sometimes substitute phone or email contact for meeting in person. Sensitivity to light and noise may lead to changes in where and how people socialize. For example, a family may rent movies to view at home, rather than going to a movie theater or visit restaurants at times when they are relatively quiet. Describing how he and his wife adjusted to her limitations, one husband in our program said that they had replaced hiking and camping with dinner and a movie.

In sum, the patient's illness may reduce the time he or she can spend with family, lead to changes in setting, and lead families to focus on less physically and mentally demanding activities.

4) Adjusting to a "New Normal"

Underlying the many practical adaptations described above is a psychological adjustment: acceptance that life has changed on a long-term basis. This is sometimes called finding a new normal and it involves coming to terms with loss.

Loss is a significant challenge both for people with CFS and fibromyalgia, and for family and friends. Those with the conditions experience loss of health and, often, loss of income, friends, valued activities, and the future they had planned for themselves.

Family and friends experience losses as well, including loss of the person they used to know, loss of some of the companionship they used to enjoy, and loss of hopes and
dreams for the future. They, too, are challenged to adjust to a different type of life than they had planned, while often having to take on new responsibilities.

Coming to terms with loss and adapting to a new life usually takes several years or more. The end point of this process is acceptance, a complex attitude that includes recognizing that life has changed, accepting the limitations imposed by illness and adjusting expectations to match new capabilities. Acceptance does not mean resignation, but rather a commitment to live the best life possible under the circumstances, recognizing that it will be a different kind of life than before.

People with CFS and FM and their families often use a combination of four strategies to build a new life.

- **Adjusting Goals to Fit Abilities**
  Focus on those things that are still possible, rather than on those that are no longer possible. This is sometimes called adjusting expectations or reframing your experience to focus on the positive.

- **Developing New Shared Interests**
  A powerful antidote to loss is to develop new interests and, from that, a new sense of purpose and meaning. A couple, in which the wife is housebound, have taken up the study of music using a course on DVD. The project is a shared activity that replaces those lost to illness.

- **Finding Positive Models**
  People with CFS/FM often report that their adjustment to long-term illness was accelerated once they found other people who had adapted successfully. Families can follow the same approach, seeking out other families who can provide both practical ideas and models of successful adaptation.

- **Develop Separate Interests**
  Well spouses usually have new responsibilities around the house, often including more child care. As a way to recharge their batteries, they need time alone or time with friends. Also, patients can benefit if they develop new interests appropriate to their limits and also new sources of support, which may be fellow patients or people who share similar interests.

5) **Sex & CFS/FM**

When CFS or fibromyalgia enters a marriage, one casualty can be intimacy between the partners. Pain, reduced energy, reduced interest, health problems of the partner, and increased responsibilities for the healthy spouse can all affect a couple’s sex life, but, like other aspects of long-term illness, intimacy problems can be reduced as well.
When we asked people in our program to describe the effects of their illness on their sexuality, all those who responded said that illness had reduced their sexual activity. Many people mentioned having a much lower level of sexual desire than before, due to factors like ongoing fatigue and pain, and the side effects of medications. Other causes of sexual problems included the effects of menopause, relationship strains, and the medical problems and/or impotence of their partner.

Even though people said that they had either reduced their sexual expression or given up sex, most also reported using a variety of strategies that have either enabled them to adapt their sexual life to their illness or to connect with their partner in other ways.

The most common adaptations are described in the article Illness & Sex: Six Strategies for Improving Intimacy.

In summary, CFS or fibromyalgia do not have to mean the end of sex. Using flexibility, experimentation and good communication, couples can continue to enjoy sex and may be able to strengthen their relationship. For those who decide that sex will no longer be a part of their relationship, a focus on other aspects of the relationship can foster closeness and caring.

6) Counseling

Because serious illness puts relationships under strain, counseling can be helpful. Many people in our program report using either individual psychotherapy, couples therapy or both as a way to sort out issues and to work through strains. If that idea appeals to you, consider looking for a counselor who specializes in helping people affected by long-term illness. Support groups can be a good source of referrals.
Chapter 3: How To Help Your Loved One & Yourself

This chapter has a dual focus. We begin with ideas about how family members and friends can help people with CFS or FM in many ways, then discuss how to take care of yourself.

How To Help The Person Who Is Ill

How To Help The Person Who Is Ill

Some help you offer the person who is ill is practical, such as taking on tasks the person with CFS or FM is no longer able to do or providing transportation for errands and medical visits. Some help is emotional, offering a listening ear or some reassurance. But perhaps the biggest aid family and friends can give is to support the person with CFS or FM in her efforts to adapt her life to long-term illness.

The severity of symptoms and sometimes even the course of CFS and FM are affected by how a person lives her day to day life. The effects are so great that lifestyle change is the treatment of choice for the two conditions. In the words of well-known CFS/FM physician Dr. Charles Lapp, CFS and FM "are best managed with adaptation and lifestyle changes....There is no drug, no potion, no supplement, herb or diet that even competes with lifestyle change for the treatment of CFS or FM."

The way you interact with the person in your life who has CFS and/or FM has a significant effect on her. It makes a significant difference to her symptoms and quality of life.

There are benefits to your quality of life as well. A person with CFS or FM who learns pacing has a much more predictable life, making planning easier and reducing uncertainty. She is also likely to be able to expand her activity level. A person who gets better sleep is likely to be less irritable and able to think more clearly.

Here’s how you can help in seven different areas.

Pacing

Pacing

Probably the single most important lifestyle change for controlling symptoms and increasing the likelihood of improvement is to adjust activity level to fit the limits imposed by illness. This approach is often called pacing.

In contrast to fighting the body with repeated cycles of push and crash, the person who adapts to limits seeks to understand the body's new requirements and to live within them. Pacing, above all, means reducing one's overall activity level. (As mentioned earlier, the average person enters our program at about 25% of normal, which means to control symptoms she must begin by reducing activity by 75%.)
Pacing also usually includes integrating regular rest periods into the day and other strategies such as:

- Short activity periods
- Switching between high-intensity and low-intensity activities
- Scheduling most demanding activities for the hours when symptoms are lower
- Recognizing limits on mental and social activity as well as physical
- Taking extra rest and reducing activity for vacations and other special events

Pacing offers the possibility of a more stable and predictable life. With pacing, people with CFS and FM can live their life according to a plan, rather than in response to symptoms, giving them a sense of managing their illness rather than the illness being in control. Learning pacing is a gradual process, usually taking a period of several years and involving the use of multiple strategies.

One way to understand the value of pacing is by contrasting it another way of living with CFS and FM: push and crash. This involves overdoing followed by recovery through rest. The amount of rest required is out of proportion to the overdoing.

To give an example of the price paid for overdoing and the value of pacing, one person in our program said that week-long visits from her daughter and granddaughter triggered relapses lasting six months. Since she learned to use pacing during the visits, her recovery time has been two days.

Family and friends can help the person with CFS or FM to adapt by accepting that she can do less than before and by acknowledging that she will need to spend more time in rest and do things in new ways (such as alternating activity and rest).

**Improving Sleep**

Poor sleep is one of the most common and troublesome issues in both CFS and fibromyalgia. Patients often experience sleep as unrefreshing; a person spends a night in bed but wakes up as tired as before. Other sleep problems are common as well, such as difficulty getting to sleep, waking in the middle of the night or early in the morning, and oversleeping.

Because sleep problems are so common and so debilitating, poor sleep is often the first symptom addressed. Treatment of sleep problems usually includes prescription medications, but lifestyle changes can also be useful. Sleep can be improved by having an environment conducive to sleep and by having good sleep habits, such as a regular time to go to bed each night. A comfortable sleep environment includes a good mattress and control of light, noise and temperature. (Noise includes snoring by the sleep partner.) Some couples solve noise problems by sleeping in separate rooms. This strategy also allows the patients greater control over other elements in the sleep environment, such as temperature.
Other factors that affect sleep include overactivity, stress and worry. Too much activity can create a sense of restlessness, sometimes call the "tired but wired" feeling. The antidotes are keeping activity within the limits imposed by the illness and having a quiet period to wind down before going to bed. Stress often leads to muscle tension, which makes falling asleep more difficult. Worry, too, can make it harder to fall asleep. Practices that reduce stress and worry will aid sleep.

Managing Stress
Stress is a challenge for everyone, but it is especially difficult for people with CFS and FM. The two conditions add new stressors and also make people more sensitive to stress. It’s as if CFS and FM reset people's "stress thermostat," so that the effects of a given level of stress are greater than they would be for a healthy person.

The combination of additional stressors and increased vulnerability creates a double challenge. Stress is multiplied at the same time that stress takes a greater toll. Controlling stress, along with pacing and improving sleep, are probably the top three approaches for managing CFS and FM.

One of the best stress management strategies is preventive: minimizing the body's stress response by avoiding stressful situations. This can include a person's avoiding foods and other substances to which they are allergic. Light, noise and crowds create stress for many patients. Avoiding those situations or limiting the period of exposure can help the patient control symptoms. Many patients are selective about their exposure to television and movies, avoiding material that is emotionally arousing and shows with rapid scene changes.

Novelty is another source of stress. It takes more energy to respond to a new situation than it does to something familiar. One response is to make life predictable. Some patients have done that through routine: living their lives according to a schedule. They have been able to reduce the surprises and emotional shocks in their lives, and thereby reduce their stress.

Fighting Cognitive Problems (Brain Fog)
Most CFS and fibromyalgia patients experience cognitive difficulties, often called "brain fog" or "fibro fog." These problems include confusion, difficulty concentrating, fumbling for words and lapses in short-term memory.

Most people with CFS and FM feel confused by sensory input coming from several sources at one time and are therefore more likely to think more clearly if noise and light are at levels they can tolerate and if sensory data is limited to one source at a time. A conversation with a CFS or fibromyalgia patient is likely to be more productive if conducted in a quiet environment free of distractions.

Another solution to sensory overload is to have an orderly physical environment. Removing clutter is a way to control brain fog by limiting sensory input. A related
strategy is to live a predictable life using routines. For example, always putting keys in the same place and having meals at the same time every day.

A final strategy for reducing the effects of brain fog is to be sensitive to time of day. Most patients have better and worse periods during the day. A patient may be able to get twice as much done if they schedule activity for good hours of the day. Similarly, discussions are likely to be more productive if held during a time when the patient is mentally sharpest.

**Managing Emotions**
Most people with CFS and fibromyalgia find that their emotions are more intense and harder to control than they were before they became ill. The technical term is labile. As one person in our program wrote, "My emotions are much more sensitive than ever before. I cry more easily, and I have less emotional reserve."

One example of intense emotions among people with CFS and FM is irritability. Patients can easily feel frustrated, which often leads to unfortunate outbursts of anger that may be directed at those around them.

We advise patients to take responsibility for the problems their illness creates for others, suggesting that if their illness affects their moods, they use a time when they are feeling well to make a plan of things to do to help them feel better when their mood is low, so they don't inflict their negative moods on others. For example, they might plan to respond to feeling irritable by taking a rest (irritation is frequently triggered by overexertion), taking a walk or listening to music.

**Special Events**
Anything out of the ordinary --a vacation, a holiday celebration or even having people over for dinner-- creates a special challenge for people with CFS and/or FM. As non-routine events, they require more energy than everyday life and can easily lead to a relapse. Family members and friends can help by supporting the person with CFS or FM in her use of strategies that reduce the cost of a special event.

The most effective strategy is to take more rest than usual, before, during and after a special event, storing up energy by taking extra rest before the event, limiting symptoms by taking extra rest during and taking whatever extra rest is needed afterwards.

The other two strategies people often use are to plan in detail and to discuss plans with others. For travel, planning may include scheduling in advance the activities for each day of the trip. It might also mean using a wheelchair or motorized cart in airports. Discussion involves sharing plans so all involved understand.

All these strategies imply that the person who is now more limited will probably have to change their role or level of involvement. They might stop cooking the meal for a holiday celebration and instead ask family members to bring one dish each. Or they might go to event, but stay for less time than when they were healthy or change their level of
involvement based on symptoms. On a trip, for example, they might opt out of some activities in order to take additional rest.

**Food Issues**

Dietary changes are common with CFS and FM. Most CFS and FM patients are intolerant of alcohol and many are sensitive to caffeine and other stimulants; sweeteners such as sugar and corn syrup; food additives; and tobacco.

About a third of CFS and fibromyalgia patients have food sensitivities or food allergies. Negative reactions include gastrointestinal symptoms such as heartburn, gas, nausea, diarrhea constipation, as well as other symptoms such as headaches, muscle pain, changes in pulse and fatigue.

Some common sources of food allergy include dairy products, eggs, soy, wheat, and corn. Often the solution is to eliminate a food or food group from the diet. Sometimes the patient's diet is restricted to a limited number of foods, calling for family accommodation. Solutions include dual meal preparation or change of diet by other members of the family.

**How To Take Care of Yourself**

Living with someone who has CFS or FM can be a stressful experience. You may take on extra responsibilities, experience financial strain, feel frustrated and resentful at times, lose companionship, face uncertainty about the future, and experience both reduced socializing and sexual difficulties.

In response to the pressures created by serious illness, here are nine ways to take care of yourself. Because the severity of CFS and FM vary, not all the suggestions will apply to all caregivers.

**Maintain Your Health**

This is the number 1 recommendation of experts on caregiving. To serve your loved one well and to avoid resentment and burnout, take time to get adequate rest, to eat well and to exercise.

**Accept Help**

When people offer to help, accept the offer and suggest specific things that they can do. If your finances allow, consider paying for help in such areas as meals, housecleaning and transportation.

**Take Time for Yourself**

Get a respite from caregiving by spending time away from the person who is ill, for example by taking up a new hobby or returning to an old one or by spending time with friends. The point is that to give yourself some time for leisure time and enjoyment, so you can recharge your batteries and also nurture relationships beyond that with their spouse.
Educate Yourself
Seek information about CFS or FM, especially strategies for reducing symptoms and improving quality of life. One source is the articles on this website. See the article Educate Yourself for a list of patient organizations, websites and books about the two conditions.

Stay Connected
Avoid isolation and reduce stress by maintaining relationships with extended family and friends. This may mean getting together regularly for exercise or cards with friends, spending time with children or any other kind of socializing that keeps you connected with others.

Consider Counseling
Be sensitive to signs of stress and consider seeing a counselor if you detect them. Signs that counseling might be appropriate include feeling exhausted, depressed or burned out, or over-reacting, such as by angry outbursts.

Counseling can be helpful for gaining perspective on your situation or to explore communication problems. You might get help in individual sessions or in joint sessions with the person who is ill.

Grieve Your Losses
Just as people with CFS and FM experience many losses, so do family and friends. They are deprived of part of the companionship the patient used to provide, as well as her work around the house and, in many cases, financial contributions. And, just as the person who is ill has lost the future she hoped for, so do family members have to adjust their dreams for the future.

Like patients, family members, too, need to grieve their losses. In the words of one patient, "I lost my health, but my husband lost the woman he married." Grieving may take several years.

Create New Shared Activities
Serious illness may make it impossible for you to spend time with the person who is ill in the same way as before, but you can develop new shared activities to do together. One couple told us they took up the study of music using courses on DVD. The husband in another couple said that once he realized his wife's new limits, they shifted from camping and hiking to dinner and a movie.

The point is to create occasions for shared pleasure, so that the relationship is strengthened and both ill and healthy members of the family don't come to see their relationships as just about illness and deprivation.
Seek Support from Other Caregivers
Fellow caregivers can offer strength, support, inspiration and models of successful adaptation. You might meet such people through patient support groups. Also, we offer a self-help course for family and friends of people with CFS and FM.