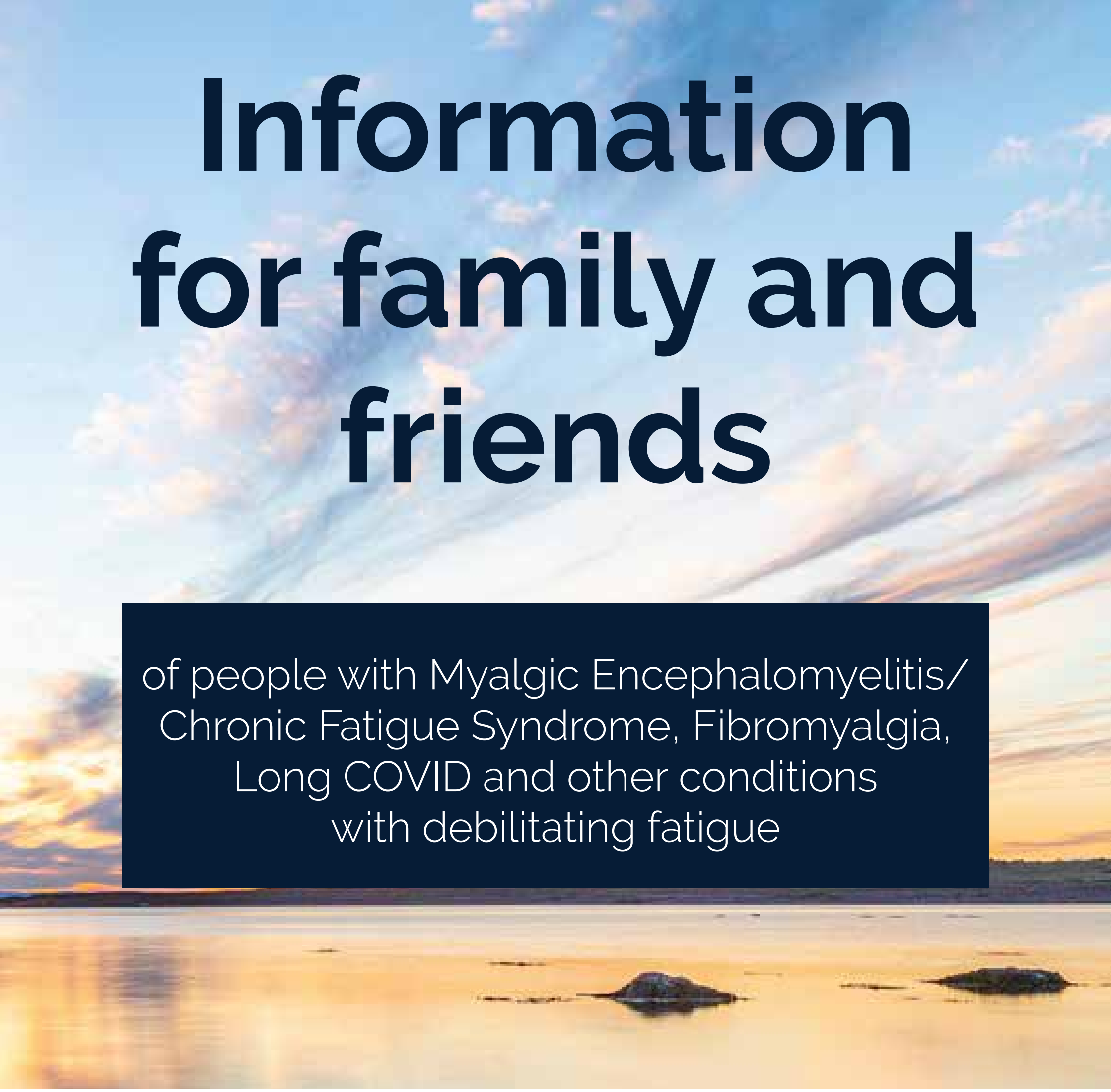

Information for family and friends

of people with Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome, Fibromyalgia, Long COVID and other conditions with debilitating fatigue

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Information for family and friends of people with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, Fibromyalgia, Long COVID and other conditions with debilitating fatigue

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1. What happens when a loved one is suffering from debilitating fatigue?

When someone you know develops symptoms of debilitating fatigue you may at first think that the problem is a lingering short-term illness. But at some point, you realise that your loved one has entered a new realm: the world of chronic illness. Instead of resuming familiar patterns and routines, the person with debilitating fatigue condition will be faced with the prospect of adjusting to a different life. Their illness will present you with challenges as well.

Here are some of the issues often faced by family members of people with debilitating fatigue conditions (some also apply to friends).

- taking on extra household tasks
- financial strains
- caregiving responsibilities
- strained relationships
- worry and uncertainty about the future
- uncertainty about how to help the person who is ill
- resentment and frustration
- grief, sadness, and depression
- increased stress
- sexual difficulties
- loss of companionship
- strained communication
- less socialising capacity
- extra parenting responsibilities

A. Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, Fibromyalgia and Long COVID

- **Overview**

The most common cause of debilitating fatigue are the conditions Myalgic Encephalomyelitis or Chronic Fatigue Syndrome (ME/CFS), Fibromyalgia (FM) and more recently the onset of Long COVID. These conditions are now widely recognized as real illnesses, not psychological problems. Diagnostic criteria have been established for ME/CFS and FM, and more recently the World Health Organisation established standard diagnostic criteria for Long COVID.

ME/CFS, FM and Long COVID are common. Research suggests that there are probably more than 250,000 with ME/CFS in Australia. Estimates of the prevalence of FM vary, but there are probably at least one million people in Australia with FM. Whilst there is no complete data, it is estimated that up to one third of people infected with COVID-19 develop Long COVID. Approximately, 50% of long COVID sufferers meet the diagnostic criteria of ME/CFS.

(The above estimates were referenced from Emerge Australia, Fibromyalgia Australia, the Australian Institute of Health and Welfare and the World Health Organisation respectively)

- **Symptoms**

The average person with one of these debilitating fatigue conditions has moderate to severe symptoms and experiences a reduction in activity level of between 50% and 85%. These conditions are characterised by the presence of several to many symptoms.

One way of understanding debilitating fatigue is the illustration of a phone battery. A well person will wake with a battery between 90% and 100% and as they go through the day the battery will reduce to 40% or 50% depending on their level of activity. Someone with a debilitating fatigue condition will wake with as little as 5% or 10% or none as their battery doesn't charge overnight like it is meant to. This means that just getting out of bed and showering takes all their battery stock.

The central symptom of these conditions is the debilitating fatigue that is often experienced as deep exhaustion. Other prominent symptoms include pain, sleep that is not refreshing and cognitive problems including confusion, difficulty concentrating, fumbling for words and lapses in short-term memory.

Other symptoms that often appear include headaches, low grade fevers, a sore throat, tender lymph nodes, anxiety, and depression, ringing in the ears, dizziness, gastrointestinal issues (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.

Another prominent symptom (particularly of Fibromyalgia) is widespread pain, jaw pain, and dry eyes and mouth.

Long COVID affects each person differently. Some have ongoing symptoms from organ damage, others will meet the diagnostic criteria for ME/CFS or a related condition. The most commonly reported symptoms of post-COVID-19 syndrome include debilitating fatigue and lung (respiratory) symptoms, including difficulty breathing or shortness of breath and a cough.

People diagnosed with either ME/CFS or FM are commonly found to have other conditions as well, such as irritable bowel syndrome, food and chemical sensitivities, sleep disorders (for example, apnea and restless legs syndrome), myofascial pain and thyroid conditions. Long COVID symptoms may resemble or overlap with both ME/CFS and FM. The most common additional medical problems are still being determined.

Below is the ME/CFS, FM and long COVID Rating Scale

It’s good to know where your family member or friend rate themselves on this scale. The numbers on the left represent an approximate percentage of a healthy person’s capacity.

100	Fully recovered. Normal activity level with no symptoms.
90	Normal activities 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 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 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.

- **Treatments and prognosis**

Because there is so far no cure for ME/CFS, FM or Long COVID, 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 person to person. Since no medication is consistently effective, treatment usually consists of a process of trial and error to find what works for an individual person. People can usually improve, or at least manage symptoms, by adjusting their activity level, reducing stress, and improving sleep

For most people, ME/CFS and FM are long-term conditions. as no cure has been developed so far. A few people recover, some people may improve over time, while others remain stable and a few decline. Symptoms of post COVID-19 condition generally improve over time, typically 4–9 months. Approximately 15 in 100 people still have symptoms at 12 months.

- **Effects**

Chronic illness is a challenge to manage because its effects are so comprehensive. Debilitating fatigue touches every aspect of life: a person's ability to work, relationships, emotions, dreams for the future and their sense of who they are.

Complicating the challenge, there is an interaction between illness and other parts of life. Debilitating fatigue restricts a person's life, but, in turn, can be worsened by how a person lives. For example, illness puts limits on a person's activity level. But, if a person with debilitating fatigue does more than their body can tolerate, overactivity causes a higher level of symptoms.

- **Interactions of illness and other factors**

The same pattern of reciprocal effects is true for other elements as well, such as the relationship between illness and stress. Living with symptoms on a daily basis is inherently stressful. In addition, illness often creates new stress because of factors such as financial pressure, strained relationships, and uncertainty about the future. In all these ways, illness increases stress.

We also know that stress often worsens symptoms. People with debilitating fatigue are very stress sensitive, so that even moderate amounts of stress can intensify symptoms, creating a feedback loop in which symptoms and a patient's reaction to them intensify one another.

Similarly, there is a two-way relationship between illness and emotions. Emotions like worry, anger, depression, and grief are normal reactions to chronic illness, understandable responses to a situation in which life is disrupted and routine replaced with uncertainty.

Most people experience a vicious cycle, in which illness intensifies emotions and then emotions, in turn, intensify symptoms. For example, people who become depressed because of their illness have a lower threshold for pain. Also, pain can be intensified by anger, because anger usually creates muscle tension.

In summary, debilitating fatigue have comprehensive effects, touching many parts of a person's life. They are much more than simple medical problems. A plan for managing them has to address all its effects, not just symptoms.

B. Your situation

Serious illness has profound effects on family and friends, not just the person who is ill. Just as each person with debilitating fatigue is different and needs to develop an individualised self-management plan, so, too, do you need to tailor your response to your unique circumstances.

- **Factors shaping your situation**

Probably the most important factor shaping your situation is the severity of your loved one's medical problems. The amount of disruption to your life and the amount of adaptation required of you will be dictated by the number and seriousness of the health issues faced by your loved one and by your relationship to them.

For those whose lives are touched only lightly by a friend or loved one with a debilitating fatigue condition, the adjustments may be relatively minor. When the illness is severe, the stress can be great and the caregiving responsibilities substantial.

A second important factor is your own circumstances (age and health) and the life stage of your family. If you are young and vigorous, your ability to take care of a person with debilitating fatigue condition is different than if you are older and perhaps dealing with your own health problems. Likewise, the life stage of your family situation is important. If you have school age children, they are a major responsibility. If your children are grown, they may be sources of help.

A third significant aspect of your situation is your finances. This will impact every family in different ways and may result in an impact on being able to meet medical costs and participating fully in the community. These families often require support to manage all factors of their financial and social commitments.

- **Coping skills and attitude**

Finally, your family's ability to deal successfully with a family member with a debilitating fatigue condition will be shaped by your coping skills and attitude. The way a person and those around them conduct their lives has a major impact on the family member and on everyone's quality of life. Your actions and those of the person with the condition can change the effects of the condition and may even change the course of the illness.

Living well with a debilitating fatigue condition requires a level of management like that for other serious, long-term conditions, such as diabetes that also take major, long-term lifestyle changes to control the illness. Your actions and attitudes will have an important effect on your loved one's symptoms. By helping them adjust to their limits and by working to create a stable and predictable environment with lowered stress, you contribute to their wellbeing.

You may not be able to change the fact that someone in your life has a debilitating fatigue condition but together you can learn new and more effective ways to deal with the condition. Research has shown that the people who do best living with chronic conditions are those who believe in their ability to exercise some control over the illness. These people do not deny that someone is ill, nor do they hold unrealistic hopes for recovery, but they have confidence they can find things to make their lives better.

Finally, there is one more factor that is important to living well with long-term illness: attitude. The approach to living with chronic illness that we have found helps people cope can be characterized as being at the same time both realistic and optimistic. We call it acceptance with a fighting spirit.

People with this attitude combine two apparently contradictory ideas. On the one hand, they accept that the illness in their life is a long-term condition. Instead of living as if the person were well or searching for a miracle cure to restore good health, people with this approach acknowledge that their life has changed, possibly forever. At the same time, they and their loved ones also have a fierce determination that they can find ways to improve quality of life through their own efforts even with a long term condition.

In summary, good coping skills and a positive attitude can make a significant difference to their condition and your quality of life.

2. Coping with the impacts of debilitating fatigue conditions

The changes brought by the onset of a debilitating fatigue condition are usually dramatic and far reaching. A person who used to be healthy now has substantially less energy than before, has trouble thinking clearly, and finds themselves easily overwhelmed by stress or even by light and sound or the weather. This chapter describes the impacts of these conditions, and strategies for addressing them.

A. Managing symptoms

There is so far no cure for either ME/CFS, FM or Long COVID, but there are many ways to alleviate the symptoms. While treatments don't heal these conditions, they can reduce pain and discomfort, bring greater stability, and lessen psychological suffering. Most people treat their symptoms using a combination of medications and life changes.

Since no medication is consistently effective in treating debilitating fatigue conditions, we recommend that people firstly find a doctor or set of health care providers who are willing to work with them to find out what works in their individual situation.

It is also very important to understand that symptom levels are affected by the actions of those around them. How a person lives with their condition and how his or her family and friends act, will intensify or help to alleviate the symptoms of the conditions.

B. Activity limits and pacing

A lot of debilitating fatigue conditions impose limits on people.
The severity of illness can vary greatly, but usually people function somewhere between about 15% and 50% of normal. People with debilitating fatigue usually can do less around the house than when they were healthy. They often need to reduce their hours at work or stop working altogether.

The limits brought by illness require many adaptations, both practical and psychological. For many people, the bigger challenge is psychological: accepting that life has changed and learning to see life in a new way. This acceptance is not resignation, but rather an acknowledgment of the need to live a different kind of life, one which honours the limits imposed by illness.

In the words of one person in our program, ‘Getting well requires a shift from trying to override your body’s signals to paying attention when your body tells you to stop or slow down’. This process of accepting limits and learning to live a different kind of life usually takes several years.

In terms of practical adjustments, perhaps the single most important strategy for controlling symptoms is for the person to adjust their activity level to fit the limits imposed by their condition. We call this ‘living within the energy envelope’ or pacing.

Rather than fighting the body, with repeated cycles of push and crash, the person seeks to understand the body’s new requirements and to live within them. Because it is not possible to do everything with limited energy, they, family members and friends must choose those things that are most important.

Family members and friends also have an important role to play in helping the person to adapt to limitations. The first and most significant is to honour the person’s limits, accepting that they can do less than before and trying to do more than the body allows intensifies symptoms. Another, as discussed in the next section, is to adjust the family workload.

C. Adjusting family roles

Debilitating fatigue usually leads to a redistribution of household and caregiving tasks: cooking, cleaning, shopping, laundry, bill paying, taking children to school & extracurriculars etc. For those things that are unable to be done or not 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 used to be done. Probably the most common solution is for other family members or friends to take over some or even many of the duties.

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. Another solution used by some families is to employ a cleaning service to take over housecleaning or to come in occasionally.

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. Some people adopt new standards for themselves. One person told us, with a smile, that she now views dust as ‘something that protects my furniture’.

While accommodations to the person’s illness are often required, they may be able to increase the amount of work done by changing how they work. For example, several short periods of meal preparation with a break in between may allow them to make dinner without intensifying symptoms. The length of work periods may be increased by sitting rather than standing.

Also, by spreading housework over a week rather than doing it all at once, someone with debilitating fatigue can avoid the push and crash syndrome. Finally, most people have good and bad times of day. It may be possible to get more done and avoid a flare up of symptoms by working during the good hours of the day.

D. Financial pressures

The financial effects of a family member with a debilitating fatigue condition varies greatly. A few people who continued working while their symptoms worsened, have told us that they wished they had evaluated their financial situation earlier and left work sooner.

Some people have been successful in gaining government financial support, including the Disability Support Pension and admission to schemes such as the NDIS. This is certainly not true for everybody and application to these schemes can be very stressful and requires time and energy.

E. Poor sleep

Poor sleep is one of the most common and troublesome issues for people with a debilitating fatigue condition. They often experience sleep as unrefreshing; spending 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.

The treatment of sleep problems usually includes prescription medications, but lifestyle changes can also be useful. The family can help by being supportive of adaptations that improve sleep. Good sleep can be aided by having an environment conducive to sleep and by having good sleep hygiene.

A comfortable sleep environment includes a good mattress and control of light, noise and temperature. Some couples solve noise problems such as snoring by sleeping in separate rooms. This strategy also allows the unwell person greater control over other elements in the sleep environment. Having a regular bedtime is also helpful.

Other factors that affect sleep include overactivity, stress and worry. Too much activity can create a sense of restlessness, sometimes called 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, including a period prior to settling of not using screens including computers and televisions. Stress often leads to muscle tension, which makes falling asleep more difficult. Practices that reduce stress and worry will aid sleep.

F. Cognitive problems

Most people with debilitating fatigue experience cognitive difficulties, often called ‘brain fog’. These problems include confusion, difficulty concentrating, fumbling for words and lapses in short-term memory. There are many strategies they can use to limit cognitive problems. The discussion here focuses on how family and friends can help.

Most people with a debilitating fatigue condition feel confused by sensory input coming from several sources at one time. They are 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, ie. having a conversation with a person is likely to be more productive if conducted in a quiet environment, free of distractions like television. Some families in which the person is bothered by sound use headphones for the sound portion of television broadcasts. In some cases, the headphones are worn by them, in other cases, by a family member.

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 for controlling the effects of brain fog 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 people have better and worse periods during the day. Probably the most common pattern is a gradual improvement as the day wears on, with a slowing down in the evening. But for some people mornings are the best times of day, for others evenings.

The important thing is that each person finds the time that works for them and their family and friends honour it. The amount of both physical and mental effort can vary greatly depending on when things are done. A person 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 they are mentally sharpest.

G. Unpredictability

People often have trouble predicting how they will feel from day to day. This often leads to cancelling or adjusting plans, sometimes at the last minute. Fluctuations in symptoms can have several causes. One is the waxing and waning common to many chronic conditions. In addition, fluctuations may be due to changes in the weather, poor sleep, overactivity or stress.

Perhaps the most common coping strategy is flexibility. Plans may have to be changed or cancelled. Family members adjust better if they recognise that unpredictability is a part of illness and have alternate activities they can do.

Some families have developed systems for understanding the person's ever-changing condition. One system involves having them rate themselves each day on a ten-point scale. A rating of 1 might be used for a very good day, with very low symptoms. A rating of 10 would mean severe symptoms and the need to stay in bed.

Some portion of symptom fluctuations can be brought under control over time. As mentioned earlier, pacing offers a way to bring greater stability to life, and therefore fewer surprises. Also, maintaining a stable environment reduces stress, which is a major trigger of greater symptoms. So a sensible response to unpredictability is a combination of flexibility and lifestyle adaptations that promote a consistent activity level, good sleep and control of stress.

H. Intense emotions

Most people with a debilitating fatigue condition find their emotions are more intense and harder to control than they were before they became ill. One participant in our program wrote, 'My emotions are much more sensitive than ever before. I cry more easily, and I have less emotional reserve'. Another said, 'Just recognising that emotions are heightened as a result of these conditions really helped me. Before learning that, I was quite puzzled by why I got upset about little things.' The strength of emotions can create a vicious cycle in which illness intensifies emotions and then emotions, in turn, intensify symptoms.

The process by which feelings intensify symptoms occurs even with positive emotions, as suggested in a comment from another participant 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'. Whether positive or negative, any experience that triggers heightened emotions, is likely to intensify symptoms.

One example of intense emotions among people with a debilitating fatigue condition is irritability. People can easily feel frustrated, which often leads to unfortunate outbursts of anger that may be directed at those around them.

We suggest that if their illness sometimes affects their moods, they use a time when they are feeling well to plan 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. Family and friends can help by encouraging them to do the things that improve their mood.

I. Stress

Stress is a challenge for everyone, but it is especially difficult for people with long-term illness and those around them. Illness adds new stressors to those that all families face, and, unlike crises, these stresses are ongoing.

There is an additional source of stress, one that is inherent in the person's illness. Most debilitating fatigue conditions are very stress-sensitive illnesses meaning they reset the person'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 for people with debilitating fatigue conditions. Stress is multiplied while they are made more vulnerable to the effects of stress.

Being supportive of a person's efforts to control stress, along with helping a person to live within the limits imposed by illness, are two of the most helpful things the family can do to promote their quality of life.

Pacing is one effective way to control stress. Pacing techniques include keeping activity level within a person's limits, taking daily rests, using routine, scheduling activity based on priorities, and timing activity for the best hours of the day. Other stress reduction approaches include de-cluttering (for example, reorganising the kitchen or discarding unused possessions), limiting exposure to media, limiting contact with some people, avoiding crowds, and making mental adjustments (such as letting go of outdated expectations).

For many people, work is a major stressor, usually because the demands of a job are greater than someone's energy envelope. Some people have responded by changing their work situation. These changes have included switching from full-time to part-time work, moving to a less demanding job, working from home, adopting a flexible schedule, and leaving the work force, usually through early retirement.

Light, noise and crowds create stress for many people. Avoiding those situations or limiting the period of exposure can help them control symptoms. Many people are selective about their exposure to screens, 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 people 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.

J. Weather and sensory overload

Two other factors that affect people with a debilitating fatigue condition is weather and sensory overload.

Changes in the weather or types of weather can affect people's symptom levels. Probably the most common reaction for people with FM is more intense symptoms during times of high humidity. The best family coping strategy is to accept that the person will suffer more and do less during these times.

As mentioned earlier, most people are sensitive to noise or light, or to sensory input coming from more than one source at the same time. The most helpful response is to tailor sensory input to the person's limits. This will often mean limiting sensory information to one type at a time, for example, talking without any background noise. It may also mean socializing with only one or a small number of people, rather than in large groups, and visiting restaurants and other public places in off-peak hours.

K. Additional medical problems

Managing symptoms is complicated by the fact that people with a debilitating fatigue condition often have one or more additional medical problems. These include irritable bowel syndrome, food and chemical allergies, myofascial pain, neurally mediated hypotension, anxiety and depression, and sleep disorders such as sleep apnoea and restless legs syndrome.

Many people with a debilitating fatigue condition 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 their diet is restricted to a limited number of foods.

3. Relationships: Stresses and strategies

Debilitating fatigue conditions create great strains in relationships, both intensifying existing sources of stress and creating new ones. The drastic changes brought by illness, together with having less energy, put family and other relationships under great strain. In this chapter, we describe relationship problems created by long-term illness and offer ways to cope with them.

A. Adjusting expectations to a 'new normal'

People with a debilitating fatigue condition typically function at 50% or less of their previous level, frequently much less. Trying to do more than their bodies allow leads to more intense symptoms and sometimes to even more restrictive limits. To the extent that all those around them can accept the limits imposed by illness, they can create a plan for a new type of life. This life requires both practical and psychological adjustments.

Practical adjustments include redistribution of household tasks, often increasing the load on the well person Because they have significantly less energy than before they were ill, people with a debilitating fatigue condition have less time for relationships than they had when healthy, creating a loss of companionship. Also, aspects of the illness, such as the unpredictability of symptoms, energy limits and sensory overload, suggest the need for adjustments.

Like the person in your life, you have experienced the loss of a dream and are challenged to adjust to a different type of life than you had planned. You have lost some part of the companionship you once had and, instead, may have taken on new responsibilities.

B. Improving communication

Serious illness puts families under great stress. Good communication can be one of the casualties. You'll find below some tips on how to improve communication with the person in your life who has a debilitating fatigue condition.

- **Scheduled relationship discussions**

A strategy for nurturing relationships and keeping discussion of issues in a problem-solving context is to set aside time regularly to discuss the relationship you have with the person in your life who is ill. One couple in our program calls it their ‘talk night’. They set aside Sunday evenings as a time to discuss any issue that is on their minds.

- **Setting and Approach**

For ‘talk night’ type conversations or other important conversations, we suggest you pick a time when both you will be at your best. Find a time when you can give good attention and the person who is ill will not be distracted by pain or brain fog, preferably during their best hours of the day.

To create an atmosphere of cooperation, consider having each person acknowledge their part in shared problems and express appreciation for the other’s efforts. Also, consider having each person ask, ‘What can I do to make your life easier?’ and each person state, ‘Here are some things you can do to make my life easier’.

- **Seek professional support to assist in communication**

The use of counsellors with experience in dealing with people dealing with chronic conditions can be useful to help you set up positive ways of dealing with communication and other everyday tasks that become an issue when someone is chronically ill.

This could be undertaken individually, as a couple or a family unit to help improve everyone’s understanding of the impact of the illness.

C. Intimacy and sex

Because of pain, reduced energy or reduced interest, a couple's intimacy is often affected for people with debilitating fatigue conditions creating another challenge for couples.

Couple's counselling can be a very positive tool to assist in communicating each partner's feelings around changes to intimacy and sex.

D. Travel

Travel, a source of enjoyment and pleasure for many people, can be difficult when someone has a debilitating fatigue condition. For most people with these conditions, however, enjoyable travel is possible if some adjustments are made.

One foundation for successful travel is realistic expectations. Because the conditions impose limits and because travel requires more energy than everyday life, people are able to do less now when traveling than when they were healthy and less on the road than they can do at home.

Adjustments to illness may include taking extra rest in the days before a trip starts, taking rests during road trips (for example, a 15-minute rest every two hours), setting limits on how many hours a day to be active, taking a full day of rest after a long drive or plane flight, keeping a flexible schedule to accommodate unforeseen events or higher than expected symptoms, and alternating an active day with a day of rest.

People with debilitating fatigue conditions have told us that they have travelled more successfully after they began planning their trips in great detail. They mentioned using books and the Internet to decide what they wanted to see, then set their itinerary based on how much activity they could do. Planning also involved packing ahead of time and, for some people, planning to use wheelchairs or motorised carts in airports. One person said that having a detailed itinerary set in advance helped him resist the temptation to do too much when away from home.

People also report having more enjoyable trips when they talk to their travel companions ahead of time about their limits and make a joint plan. The person with a debilitating fatigue condition may need extra rest, so there may be some activities they won't be able to do. They may join in some activities but forego others. Taking extra rest before, during and after a trip is a common travel strategy. Store up energy by taking extra rest before a trip, limit symptoms during a trip by taking extra rest while away and take whatever extra rest is needed after to get back to normal.

E. Taking care of yourself

Living with someone with a debilitating fatigue condition is a stressful experience. Here are six strategies you can use to take care of yourself, responses to the pressures created by the presence of serious illness in your family.

- **Maintain your health**

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, house cleaning and transportation.

- **Take time for yourself**

Get respite from caregiving by spending time away from the person who is ill, for example by pursuing a hobby. The point is to give yourself an opportunity for leisure and enjoyment.

- **Seek support from other caregivers**

Fellow caregivers and care organisations can offer strength, support, inspiration, and models of successful adaptation.

- **Stay connected**

Avoid isolation by maintaining relationships with extended family and friends.

- **Consider counselling**

Be sensitive to signs of stress in yourself and consider seeing a counsellor if you detect them. Signs that counselling might be appropriate include feeling exhausted, depressed or burned out, or overreacting, such as by angry outbursts. Counselling 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 family member who is ill.

4. Conclusion

Building a new life includes creating new activities to do with your family member who is ill. The new activities replace ones lost because of illness and counteract the temptation to dwell on illness and loss. One couple in which the wife is housebound have taken on the study of music together. Because illness can be all consuming, it may take some deliberate efforts to break through. The point is to create occasions for shared pleasure, so that both ill and healthy members of the family don't come to see their relationships as just about illness and deprivation.

In 1987 an American author, Emily Perl Kingsley, wrote an essay titled "*Welcome to Holland*" about having a child born with a disability. Her words are also relevant to someone being diagnosed with a chronic illness and having their plans and dreams suddenly altered.

'Holland!?' you say. 'What do you mean Holland? I signed up for Italy! I'm supposed to be in Italy'. But there's been a change in the flight plan. You have landed in Holland. And there you must stay. The important thing is that it's just a different place. You must buy new guidebooks. You must learn a whole new language. And you will meet a whole new group of people you would not otherwise have met. It's slower paced than Italy, less flashy than Italy. But after you've been there a while, you look around, and you begin to notice that Holland has windmills, Holland has tulips, Holland even has Rembrandts.
So, welcome to Holland.

Along with the person in your life, you have landed in an unexpected destination. You have experienced the loss of a dream and are challenged to adjust to a different type of life than you had planned. You have probably lost some companionship and, instead, may have taken on new responsibilities. But you have a choice to dwell on what you have lost or to seek out new possibilities.

Chronic illness has profound effects, changing every part of life: how much a person can do, people's moods, their relationships, their finances, their hopes, and dreams. Even though you may not have the ability to change the fact that someone in your life has a debilitating fatigue condition there are many things you can do to improve their, and your, quality of life.