

Table 3. Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic, and Treatment Protocols. Carruthers et al., *Journal of Chronic Fatigue Syndrome* 11, no. 1 (2003): 7-115.

In order to be diagnosed with CFS, a patient must have the following:

1. **Fatigue:** new onset, unexplained recurrent physical and mental fatigue that significantly alters activity level.
2. **Post-Exertional Fatigue:** After physical activity there is an increase in symptoms and/or an extended recovery period usually lasting a day or more.
3. **Sleep Dysfunction:** There is unrefreshed sleep and/or difficulty getting to or maintaining sleep.
4. **Pain:** There is a significant degree of muscle pain. Pain can also be experienced in the joints and is often widespread and changes location. Often there is a new onset of headaches post-illness. Headaches may be of a different quality and in a different location than in the past.
5. **Two or more Neurological/Cognitive Manifestations:** confusion; impairment of concentration and short-term memory; disorientation; difficulty with information processing, categorizing, and word retrieval; and perceptual and sensory disturbances. The Expert Panel describes overload phenomena, cognitive and sensory—i.e., heightened sensitivity to lights and noise—and/or emotional overload, which may lead to “crash” periods and/or emotional symptoms.
6. At least one symptom from two of the following categories:
 - a. **Autonomic Manifestations:** blood pressure abnormalities, particularly when rising from lying or seated position, often called delayed postural hypotension; light-headedness; nausea and irritable bowel syndrome; urinary frequency and bladder dysfunction; heart palpitations; shortness of breath with physical activity.
 - b. **Neuroendocrine Manifestations:** “Thermostat” regulation is lost, presenting as lowered body temperature with significant daily fluctuation, sweating episodes, recurrent feelings of feverishness and cold extremities; intolerance of extremes of heat and cold; significant weight change—lack of or abnormal appetite; worsening of symptoms with stress.
 - c. **Immune Manifestations:** Tender lymph nodes; recurrent sore throat; recurrent flu-like symptoms; general malaise; new sensitivities to food, medications, and/or chemicals.
7. The illness is chronic and lasts for at least six months in adults, three months in children. It usually has a distinct onset, although it may be gradual.

Hope and Help for

CHRONIC FATIGUE SYNDROME AND FIBROMYALGIA

Second Edition

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Table 4. A Pediatric Case Definition for Myalgic Encephalomyelitis and

Chronic Fatigue Syndrome. Jason et al., Journal of Chronic Fatigue Syndrome 13, no. 2:13 (2006): 1-44.

Definition of ME/CFS for Children	
I.	Clinically evaluated, unexplained, persistent or relapsing chronic fatigue over the past 3 months that:
A.	Is not the result of ongoing exertion
B.	Is not substantially alleviated by rest
C.	Results in substantial reduction in previous levels of educational, social and personal activities
D.	Must persist or recur for at least three months
II.	The concurrent occurrence of the following classic ME/CFS symptoms, which must have persisted or recurred during the past three months of illness (symptoms may predate the reported onset of fatigue).
A.	Post-exertional malaise and/or post-exertional fatigue. With activity (it need not be strenuous and may include walking up a flight of stairs, using a computer, or reading a book), there must be a loss of physical or mental stamina, rapid/sudden muscle or cognitive fatigability, post-exertional malaise and/or fatigue and a tendency for other associated symptoms within the patient's cluster of symptoms to worsen. The recovery is slow, often taking 24 hours or longer.
B.	Unrefreshing sleep or disturbance of sleep quantity or rhythm disturbance. May include prolonged sleep (including frequent naps), disturbed sleep (e.g., inability to fall asleep or early awakening), and/or day/night reversal.
C.	Pain (or discomfort) that is often widespread and migratory in nature. At least one symptom from any of the following: Myofascial and/or joint pain (Myofascial pain can include deep pain, muscle twitches, or aching and sore muscles. Pain, stiffness, or tenderness may occur in any joint but must be present in more than one joint and lacking edema or other signs of inflammation). Abdominal and/or head pain (May experience eye pain/sensitivity to bright light, stomach pain, nausea, vomiting, or chest pain. Headaches often described as localized behind the eyes or in the back of the head. May include headaches localized elsewhere, including migraines).
D.	Two or more neurocognitive manifestations: Impaired memory (self-reported or observable disturbance in ability to recall information or events on a short-term basis) Difficulty focusing (disturbed concentration may impair ability to remain on task, to screen out extraneous/excessive stimuli in a classroom, or to focus on reading, computer/work activity, or television programs) Difficulty finding the right word Frequently forget what wanted to say Absent mindedness Slowness of thought Difficulty recalling information Need to focus on one thing at a time Trouble expressing thought Difficulty comprehending information Frequently lose train of thought New trouble with math or other educational subjects
E.	At least one symptom from two of the following three categories: I. Autonomic manifestations: Neurally mediated hypotension, postural orthostatic tachycardia, delayed postural hypotension, palpitations with or without cardiac arrhythmias,

dizziness, feeling unsteady on the feet—disturbed balance, shortness of breath.
Neuroendocrine manifestations: Recurrent feelings of feverishness and cold extremes, subnormal body temperature and marked diurnal fluctuations, sweating episodes, intolerance of extremes of heat and cold, marked weight change—loss of appetite or abnormal appetite, worsening of symptoms with stress.
Immune manifestations: Recurrent flu-like symptoms, non-exudative sore or scratchy throat, repeated fevers and sweats, lymph nodes tender to palpation—generally minimal swelling noted, new sensitivities to food, odors, or chemicals.

III. Exclusionary conditions:

A. Any active medical condition that may explain the presence of chronic fatigue, such as:

1. Untreated hypothyroidism
2. Sleep apnea
3. Narcolepsy
4. Malignancies
5. Leukemia
6. Unresolved hepatitis
7. Multiple Sclerosis
8. Juvenile rheumatoid arthritis
9. Lupus erythematosus
10. HIV/AIDS
11. Severe obesity (BMI greater than 40)
12. Celiac disease
13. Lyme disease

B. Some active psychiatric conditions that may explain the presence of chronic fatigue, such as:

1. Childhood schizophrenia or psychotic disorders
2. Bipolar disorder
3. Active alcohol or substance abuse—except as below:
Alcohol or substance abuse that has been successfully treated and resolved should not be considered exclusionary.
4. Active anorexia nervosa or bulimia nervosa, except as below:
Eating disorders that have been treated and resolved should not be considered exclusionary.
5. Depressive disorders

IV. May have presence of concomitant disorders that do not adequately explain fatigue, and are, therefore, not necessarily exclusionary.

A. Psychiatric diagnoses such as:

1. School phobia
2. Separation anxiety
3. Anxiety disorders
4. Somatoform disorders
5. Depressive disorders

B. Other conditions defined primarily by symptoms that cannot be confirmed by diagnostic laboratory tests, such as:

1. Multiple food and/or chemical sensitivity
2. Fibromyalgia

C. Any condition under specific treatment sufficient to alleviate all symptoms related to that condition and for which the adequacy of treatment has been documented.

D. Any condition that was treated with definitive therapy before development of chronic symptomatic sequelae.

E. Any isolated and unexplained physical examination, laboratory or imaging test abnormality that is insufficient to strongly suggest the existence of an exclusionary condition.

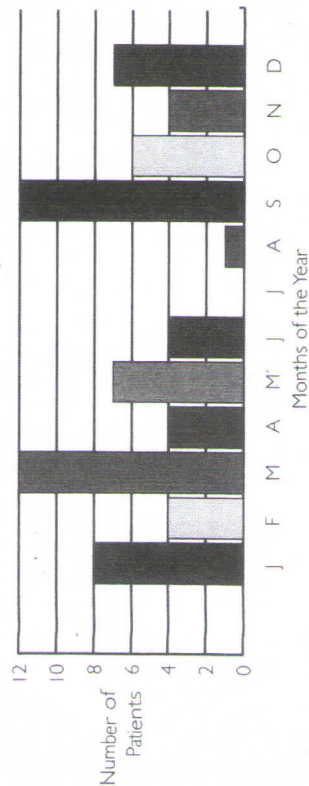
Immune Symptoms

Patients often have sore throats, tender glands (lymph nodes), flu-like symptoms, and general malaise (vague feeling of illness). These symptoms can come and go and are often present at the beginning of the illness. Allergies may appear, and new sensitivities to food, drugs, and chemicals can often present, even in the absence of an allergic history.

Length of Illness Requirements

There are some differences in the time frame for the diagnosis of CFS and FM. For CFS, usually the symptoms begin suddenly and persist for longer than six months. In children, the diagnosis can be made after three months. In some people, the onset of illness is more gradual. In the case of FM, the widespread pain must persist for at least three months for a diagnosis to be made. MCS has no time frame attached to its diagnosis.

As shown in the graphs below and on the next page, a study of 134 CFS patient questionnaires that were reviewed by Dr. Logan showed that most cases of CFS that have a sudden onset occur during the Northern Hemisphere flu season, which occurs yearly from September to March.



How are CFS/FM and Depression Different?

- Desire and motivation to be active is present in CFS/FM. Depressed patients lose their motivation and can't get going; they have inertia.
- Intensity of pain/fatigue is usually higher in CFS/FM.
- Sudden onset is more common in CFS/FM.
- More severe neurocognitive deficits are seen in CFS/FM.
- Hypersensitivities and numerous bodily symptoms, while present in depression, are more common to CFS/FM.
- The level of exercise that can improve the mood in depression may worsen CFS/FM symptoms.

FATIGUE SYNDROME, CHRONIC and click the "go" button. For fibromyalgia information, enter **FIBROMYALGIA** and click "go."

Centers for Disease Control (CDC) and Prevention

The CDC provides considerable information about CFS on their Web site. Go to their CFS home page at <http://www.cdc.gov/ncidod/diseases/cfs/index.htm>

References for MCS

References for multiple chemical sensitivity can be found at the Web site at Women's College Hospital site of Sunnybrook and Women's College Health Sciences Centre at <http://www.womenshealthmatters.ca>. Under the title *Women's Health Matters*, click Enter, then in the topic list on the lefthand side of the page, click Health Centres, then Environmental Health.CFS, FM, and MCS are all present. Another helpful site is www.mcs-global.org.

tured by standard procedures) in their ability to boost blood glutathione levels. Proteins+ is a high-quality, cysteine-rich whey product currently manufactured in Canada.

NICOTINAMIDE ADENINE DINUCLEOTIDE (NADH)

Widely available in North America, NADH is a natural co-enzyme that is specially prepared so that it maintains oral stability. It is reported to improve the production of cellular energy by boosting the levels of adenine triphosphate (ATP). It is well known that ATP is the fuel source for cellular energy, and there is no question NADH that occurs naturally in the human body is crucial in the production of energy. It seems reasonable, then, that NADH supplementation may be of value in conditions such as CFS where cellular energy is less than optimal. Indeed, ENADA® has been the subject of a small but well-designed clinical trial involving CFS patients at Georgetown University. This pilot study, using 10 mg daily, showed that 31 percent of the CFS patients had improvement in various symptoms versus 8 percent of the placebo group.

As a result of the pilot study, numerous Web sites sprung up selling and promoting NADH as the magic bullet for CFS (and a host of other neuropsychiatric illnesses). This typical "coral-calcium-esque" marketing continues. Clinical experience indicates that NADH may be most useful when combined with other antioxidants. Remember that antioxidants interact with each other, working in a synergistic fashion. Bottom line, NADH is a potent antioxidant and may offer some benefit when combined with other plant- and nutrient-based antioxidants in CFS/FM symptom reduction.

MAGNESIUM AND MALIC ACID

There have been some reports in the medical literature suggesting that magnesium may be of value in the treatment of CFS and FM. Magnesium is involved in more than three hundred enzyme reactions in the human body and is essential in energy produc-

tion. Magnesium is of particular importance to the health of the central nervous system, as low levels of magnesium (and high levels of aluminum) are associated with dementia. Research published in the journal *Lancet* showed that CFS patients had low levels of magnesium and that intra-muscular injections with magnesium were helpful in treatment. Other researchers have published findings in the *Journal of the American Dietetic Association* (1996) and the *International Journal of Neuroscience* (2003) indicating that more CFS patients have low levels of red blood cells and serum magnesium than controls. Belgian researchers suggest that some CFS patients have "subclinical" magnesium deficiency—there are no overt symptoms of magnesium deficiency and lab values may be within normal range, yet magnesium intake, absorption, and bioavailability may be clinically relevant to a variety of symptoms.

In the case of FM, the investigations into magnesium levels have also drawn inconsistent results. The long and the short of it is that there appears to be some abnormalities in magnesium metabolism. A placebo-controlled study, published in the *Journal of Rheumatology* using magnesium (450 mg) and malic acid (1,200 mg) did not show any clear value in reducing the symptoms of FM. Malic acid is a fruit acid that is found in high amounts in apples; its chemical anion form malate is critical in cellular energy production. Interestingly, when the placebo arm of the study was discontinued and participants were put on labelled doses up to 900 mg of magnesium and 2,400 mg of malic acid, there were significant improvements in FM symptoms. Placebo effect? Probably, but only further research will determine if the dose in the controlled study was too low. In the clinical setting, many patients report that the magnesium/malic acid combination is a helpful one. Perhaps magnesium and/or malic acid may be most helpful to a subset of CFS and FM patients.

In the meantime, we do know that oral magnesium has been shown to be effective in the management of migraine headaches and a number of symptoms associated with premenstrual syn-

dosages that will help to make you feel better but at the same time not aggravate your symptoms. This chapter discusses some of the more commonly prescribed medications used to treat the symptoms of CFS/FM. Just to stress again, there is no magic pill for any of the symptoms in CFS/FM. There must be a lot of hard work by yourself and your doctor, trying various medications to see which one or combinations work best in your particular body. It really helps when you keep a diary of your symptoms and their intensity so that you can take it to your doctor's visits. This will help you and your doctor determine which medication is working best.

One of the best things about the human body is our ability to forget a symptom when it disappears. Kind of like forgetting the severe pain of childbirth—which allows you to consider having a second child. If a woman actually remembered the pain of childbirth on an ongoing basis, most families would only have one child.

Often patients forget to tell me about the symptoms that disappear, an indication that a medication is working. That's why keeping activity logs and tracking not only problems but also improvements is so important.

SLEEP MEDICATION

By the time patients see me they have usually already experienced ongoing sleep disorders, sometimes for years. Since I am a "doctor of last resort," this is often where I begin to try to help patients. After I have gone through the sleep hygiene routine and the other modalities to help sleep have been exhausted, I explore the use of medications to help a patient sleep. Just to be clear, there is not a pill out there that will bring back your restorative deep sleep, the problem that all CFS/FM patients have. The sleeping pills are used in order to help you feel that you have given your brain a break for at least a few hours. The pills will not therefore make you feel refreshed in the morning; some pills will even make you feel groggy in the morning. This is the art of

individualized. In the United States patients report that Ambien is often helpful.

Benzodiazepines (e.g., clonazepam)

Although fatigue is a major symptom of CFS (and can be found in FM too), patients often report feeling "wound up" or "tired yet wired." If you are wired, relaxation techniques can help your medications work more effectively. Benzodiazepines are known as sedative-hypnotics. They can help to calm you, reduce anxiety, and treat insomnia. They work by depressing a part of the brain called the reticular activating system that regulates how active the brain is. They also help with restless leg syndrome if this is a part of the sleep disturbance. Clonazepam often works well by itself or in combination with Sinequan.

PAIN MEDICATION

Pain medication includes anything that you put into your body to combat pain. It includes over-the-counter medications and herbs such as aspirin, Tylenol, Advil, and Lakota. Often patients forget to mention the fact that they are taking over-the-counter pills and herbs in addition to their prescribed medications. It is vital to tell your doctor everything. Why? Because all of these things are, biochemically, medicine at a cellular level and have the potential to interact with one another and magnify the effect in the body. Pharmacists have access to drug and herbal interaction charts. Your doctor can phone for information if he/she doesn't have on-line access in his/her medical office. The total load of over-the-counter medications, prescription medications, and herbal medications all must be detoxified by the liver and kidneys before they leave the body. So work together with your doctors, both medical and naturopathic, so they know the entire picture and not just a piece of the medicinal puzzle.

Omega-3 and Oils (Evening Primrose Oil)

The more the omega oils are studied, the more it is realized that these need to be in balance to support healing in the body. This

is particularly true in the area of pain management. Supplementing with these oils in a balanced ratio helps reduce the inflammatory process by reducing the amount of inflammatory cytokines in the body. In the CFS/FM patient population, this is extremely important. In fact, some of my patients have been able to reduce the amount of pain medication required when they use the proper supplements and vitamins and rid their diets of additives, pesticides, and food allergies. Please see chapters 4 and 5 for more information.

Non-Steroidal Anti-Inflammatory Drugs (NSAIDs, e.g., ibuprofen, Naproxen)

Medications in the anti-inflammatory group work much better if the previous corrections have been made in the different areas of the body: eliminating sugars, pesticides, and food allergies; balancing the omega-3 and -6 oils; exercising or walking as tolerated; practicing relaxation techniques and massage; and using a sleep routine. All of these changes will help the body reduce inflammation at the cellular level so less medication is needed. The drugs included as anti-inflammatories start with the common over-the-counter drugs aspirin and ibuprofen. They work by inhibiting the production of prostaglandins, hormone-like substances that cause swelling and pain (inflammation) in the injured tissue. By blocking the production of prostaglandins in the tissue, stimulation of the nerve endings is prevented so that no pain signal passes to the brain. CFS/FM patients commonly use NSAIDs to reduce inflammation, and some report them to be quite helpful while others find no benefit. NSAIDs have been shown to be effective in the treatment of the following overlapping conditions common to CFS/FM patients: osteoarthritis, rheumatoid arthritis, and chronic low back pain.

Some prostaglandins are beneficial and are involved in maintaining the protective fluid lining in the stomach. Therefore, one of the major side effects of NSAIDs is the risk of developing stomach upset, stomach ulcers, and blood in the stool. COX-2

inhibitors are a newer class of NSAIDs. Unfortunately, COX-2 inhibitors have been associated with side effects including heart problems and stroke. As a result, they have been either withdrawn completely or used much more cautiously than when they were initially introduced. In my opinion, medication from this group is best used in a pulse fashion, meaning they can often be used successfully intermittently or for short periods of time in the patient who has been properly screened for safe use.

Muscle Relaxants (e.g., Flexeril, Baclofen)

Research supports the use of the muscle relaxant cyclobenzaprine in the treatment of CFS/FM patients with pain, sleep disorders, or irritable bowel syndrome. FM sufferers seem to have less pain and fatigue, fewer painful trigger points, and improved sleep on this drug. Tizanidine (Zanaflex) is another muscle relaxant that has shown to be useful in the treatment of the following conditions associated with CFS/FM: chronic daily headaches, low back pain, sleep, and pain. It is reported that Tizanidine can reduce the amount of substance P, an important consideration in patients with FM. Substance P is the neurotransmitter involved in the pain response. If you bite into a hot chili pepper, substance P will be released and, well, you know the consequences. FM patients have been shown to have abnormally high levels of substance P, much higher than healthy adults and CFS patients. Diazepam/Valium is an excellent muscle relaxant that can be used. It is best used intermittently for pulsed periods due to the loss of effectiveness over time and the possibility of tolerance when severe muscle spasm is present.

Drugs for Pain (Analgesics)

Analgesics relieve pain. They include common over-the-counter drugs such as acetaminophen (better known as Tylenol) and stronger narcotic prescription drugs including codeine, oxycodone, ramadol, hydrochloride, morphine, and fentanyl. Like NSAIDs, acetaminophen only provides minor pain relief. Stronger pain relief may be achieved when acetaminophen is

lymphocyte subsets in the blood—similar to the testing done on AIDS patients. This testing often shows decreased T suppressor lymphocyte subsets and decreased natural killer cells. This shows a shift in the immune system and is commonly seen in patients with CFS. In the United States measurement of natural killer cell activity is also available. This activity is often decreased. What this means is that the surveillance arm of the body's immune system is functioning below normal. It is interesting to note that I have not seen an increase in cancers in this patient population so far. But it also means that if you have CFS and you have a history of cancer in your family you must make sure that you are properly screened on an ongoing basis to try to detect a cancer early and get treatment early, because we just don't know if there is an increased risk if you have CFS/FM.

BRAIN IMAGING

We can be thankful that modern brain imaging techniques can look under the skull to uncover even subtle abnormalities in the brains of those with CFS/FM. Exciting new studies using modern brain imaging validate these illnesses. This research shows differences in the nervous system of CFS/FM patients versus patients with other illnesses and healthy controls. The studies are relatively small, and certainly larger brain imaging studies still need to be done. However, the results show that CFS/FM actually is “in the patient's head”! Here are some of the findings.

- Decreased blood flow to some areas of the brain on the brain SPECT scan.
- Decreased glucose uptake by certain areas of the brain.
- Small lesions in various areas of the brain on the MRI scan. These are known as “white matter abnormalities,” and are also observed in multiple sclerosis. The CFS patients with MRI brain abnormalities reported being more physically impaired than those without brain abnormalities on the MRI scan. (D. B. Cook et al., Relationship of brain MRI

sonal responsibility from the patient. Sometimes patients are asked to enter into a contract with the doctor when prescription pain medications are used. This includes full disclosure of all pain medications and treatments, past drug and alcohol history, family drug, and alcohol history, agreement for only one physician to prescribe pain medication, keeping a pain diary to record pain levels and the amount and time the medication was taken, and agreeing to random drug testing. This information is available online in a publication by the College of Physicians and Surgeons of Ontario. (For the *Reference Guide for Clinicians on Evidence-Based Recommendations for Medical Management of Chronic Non-Malignant Pain*, please see www.cpso.on.ca/publication; scroll down to page 19.) This is where I practice medicine and I am governed by this college. Each state or province has guidelines that determine how physicians can practice medicine. Find out what the regulations are for your area.

Doctors are required to keep records of all narcotic medications and to document the effects of the pain medication in use. For better pain control and to eliminate peaks and valleys of pain control it is advantageous to the patient to switch from short-acting to long-acting analgesics if possible. Long-acting narcotics usually have *contin* as part of their name. The *contin*s are usually better for the patient as there are fewer side effects. For example, hydromorph *contin*/hydromorphone, the longer-acting slow-release form of morphine, has fewer side effects than morphine, which is the shorter-acting form. The longer-acting or *contin* products last for six to twelve hours depending on the individual medication. In addition there are long-acting patches such as the fentanyl patch *Duragesic*. It lasts for approximately three days in most patients. Longer-acting medications give better pain control to the patient and as a result patients have a better quality of life. Usually when you are on long-term pain management you are required to visit your doctor on a regular basis, monthly or even more often. Medication is often given out at best on a monthly basis and at worst on a daily basis by the pharmacist. If

Anti-Epileptics (e.g., Neurontin)

This class of drugs is usually used to treat epileptic seizures, but they are also widely used as an adjunct to treat various conditions with severe chronic pain. Many of these drugs work by increasing nerve transmission or by blocking certain channels involved in nerve transmission. They are structurally related to the neurotransmitter GABA. Neurontin/gabapentin and Lyrica/Pregabalin are examples of this class of medications.

Antidepressant Medication

Reactive depression can be a part of any chronic illness. Chronic fatigue syndrome and fibromyalgia are no exception. Antidepressants have received a lot of negative press lately, but there is a time and a place for each modality. If all of the other modalities have failed, including talking therapy of some kind like cognitive behavioral therapy, supportive counseling, a trial of therapeutic dose of omega-3 fish oil, etc., and the patient is severely depressed, a trial of antidepressants might help the patient cope with their severe depression. Antidepressants help give patients time to sort out emotional reaction. The same advice—start low and go slow—is applicable for this group of medications. Also, adverse reactions may occur with these drugs, and you should know what to expect before you start them. Any medication can have a paradoxical reaction or the opposite reaction to what is expected. So if you feel *more* depressed when you start an antidepressant, stop taking it and phone your doctor immediately. If the doctor is not available, go immediately to the emergency room and get some medical help.

If the antidepressants are not successful and the patient is suicidal the patient must be admitted voluntarily or committed to a hospital for treatment to prevent suicide. Suicide is a permanent solution to a temporary problem. Most, but not all, episodes of depression eventually improve on their own, even if left untreated. However, many patients do not have the coping skills or energy to ride it out and can benefit dramatically from the cor-

REMEMBER, SUICIDE IS A
PERMANENT SOLUTION
TO A TEMPORARY PROBLEM.

rect type and dose of antidepressant. Patients do commit suicide as a result of these illnesses. It is more common than you think. Often it is associated with being poor, isolated, depressed, and worst of all in chronic pain, either undertreated or untreatable pain. Suicide is devastating to the patient's family and friends, who usually just didn't realize "how bad it was."

So please—if you are depressed or in severe pain go for help now. Don't give up! Phone a suicide crisis help line. If you don't know the number, phone the operator. She will call for you. Help is a phone call away. Believe it! Remember, suicide is a permanent solution to a temporary problem.

Tricyclic Antidepressants (TCAs, e.g., Amitriptyline, Doxepin)

Most drugs in this category work by increasing the concentration of certain brain neurotransmitters, specifically serotonin and/or norepinephrine (also known as noradrenaline), by blocking their reuptake by nerve cells in the brain. They are helpful for treating the reactive depression many CFS/FM patients suffer from, called *reactive* because the depression occurs as a reaction to being chronically ill. They may also be prescribed solely for pain relief, especially with fibromyalgia.

Serotonin is a well-known neurotransmitter that helps regulate mood, pain, and sleep. Research has found that patients with CFS/FM poorly process serotonin or have low levels of it. Decreased serotonin levels may lead to alterations in substance P (a hormone involved in the pain response) and deep, delta-wave sleep cycles, which may be one of the reasons FM sufferers experience widespread pain. Abnormal processing of serotonin

may also be the reason why CFS/FM sufferers have a lack of restorative deep sleep. Sleep is not only about quantity, high-quality sleep is essential in the production of certain growth hormones that repair and restore muscles. Furthermore, serotonin increases the efficiency of endorphins, the body's natural painkillers. TCAs also have the ability to affect other brain neurotransmitter channels involved in the pain response. Studies have shown that TCAs are beneficial in treating some of the associated syndromes of CFS/FM, such as irritable bowel syndrome, temporomandibular joint syndrome, and chronic low back pain, as well as in the prevention of recurrent chronic tension-type headaches.

Selective Serotonin Reuptake Inhibitors (SSRIs, e.g., Paxil, Zoloft)

These drugs work in a similar fashion to TCAs in that they increase the concentration of serotonin in the brain. However, they often have fewer side effects than TCAs because, as their name suggests, they specifically block the reuptake of serotonin in the brain's nerve cells and don't affect the other brain neurotransmitters. A concern for some CFS/FM patients is that SSRIs may worsen sleep disturbances, as one of their potential side effects is insomnia. Therefore it is best to take them first thing in the morning, and for some patients, TCAs may be a better option in any case. It is ultimately dependent upon the individual's reactions to the medication. However, SSRIs are very effective in regulating mood. Indeed, SSRIs are widely used in the field of psychiatry for the following uses: depression, anxiety, and phobias. Like TCAs, SSRIs may also help to prevent the recurrence of chronic tension-type headaches.

Dual Reuptake Inhibitors (DRIs, e.g., Effexor)

Like TCAs, these drugs increase the concentration of both serotonin and norepinephrine in the brain by blocking their reuptake by nerve cells. However, unlike TCAs, DRIs don't affect other brain neurotransmitter systems; therefore, they have fewer

(also acts as a good stimulant in low dose) ↑

side effects. Venlafaxine/Effexor is the only DRI currently available in the United States and Canada. A study has shown that it is effective in preventing migraines and tension headaches, and in high doses it can treat multiple symptoms of FM. Milnacipran is a DRI only available in Europe and Japan. It is in development in the United States for the treatment of FM, since studies have shown that it improves pain, fatigue, mood, and sleep in these patients. *

MEDICATION TO HELP LOW BLOOD PRESSURE

Adrenergic Drugs

This class of drugs contains commonly prescribed heart medications. In CFS/FM they are used to treat low blood pressure and elevated heart rate. These symptoms are likely related to the body's low blood volume and the difficulty with regulating the autonomic nervous system associated with the function of the heart. Adrenergic drugs can alter nerve transmission in pathways involved in the regulation of blood pressure, heart rate, and the diameter of bronchi. They are used to treat CFS/FM patients in an effort to address low blood pressure when standing (orthostatic hypotension), low blood pressure when standing with an irregular heart rate (postural orthostatic tachycardia syndrome, or POTS), and dizziness. Alpha-adrenergic agonists help to prevent orthostatic hypotension and dizziness by making the diameter of veins smaller, which helps to prevent too much blood from pooling in the lower body when you stand. Beta-adrenergic agonists (better known as beta blockers) can help to regulate orthostatic blood pressure and heart rate in POTS by reducing heart rate and by increasing the filling time of the heart.

Glucocorticoids (e.g., Florinef)

Fludrocortisone is a corticosteroid (or glucocorticoid) that has not been found to be effective when used on its own, but when it is combined with alpha-adrenergic agonists or beta-blockers, it has sometimes been found to be effective in the treatment of

orthostatic hypotension, POTS, or dizziness. This drug works by increasing the amount of sodium and water in the body. Two studies have shown that short-term, low-dose use of corticosteroids provided some improvement in fatigue. This is a case where clinical experience and the individual presentation of CFS/FM symptoms will help your doctor determine an appropriate dose. Long-term use has not clinically shown to be very effective in my experience.

IMMUNE DYSFUNCTION MEDICATION

Immune Stimulator and Viral Modulator

Although the cause of CFS is not known, research suggests that a dysfunction of the immune system, often started by a viral infection, may play an important role in this condition. Therefore, immune stimulators and viral modulators, such as Ampligen, are sometimes prescribed. It is usually prescribed to CFS patients with abnormalities in enzyme systems that are involved in immune and antiviral activities in the body. Studies have shown that Ampligen can produce improvements in exercise capacity, memory and cognitive ability, and activities of daily living, and lead to a reduction in visits to health care providers. Ampligen is not routinely prescribed to most patients as it is currently only available in an intravenous product form.

In addition, new research suggests that Valtrex/valcyclovir may be of benefit in CFS by limiting replication of the herpes family viruses. A recent trial demonstrated that Valtrex is effective in limiting the replication of Epstein-Barr virus (EBV) in a four-month controlled study. This is significant because CFS/FM patients often have high EBV antibodies and, at least for some, the reactivation of EBV may contribute to symptoms and the course of the illness.

Imunovir (isoprinosine) is another medication that is being studied in the treatment of CFS. Clinical improvement

in chronic fatigue syndrome has been associated with enhanced natural killer cell-mediated cytotoxicity (*Journal of Chronic Fatigue Syndrome*, 2003). A larger Phase II drug trial investigating its effects in CFS patients is ongoing as of this writing.

INFECTIONS

The use of antibiotic therapy is indicated for the treatment of infections. In my experience some patients have infections that can be difficult to diagnose. They may be bacterial infections in the urinary bladder, ongoing dental infections, or chronic sinus and bronchitis infections, to name a few. Some of these infections, such as HHV6 and mycoplasma, may need special tests such as PCR testing, which may not always be available in some medical systems (for example, Canada).

One especially difficult infection to diagnose is chronic Lyme disease. The diagnosis of chronic Lyme disease by specialized Western blot testing is also indicated if the patient has potentially been exposed to ticks that carry the Lyme spirochete. This is a difficult area of medicine at the moment because the diagnosis of chronic Lyme disease is complicated even when this special testing is done in the laboratory. The testing is not straightforward. This is an entire subject by itself in an evolving field of medicine called infectious disease. From my common sense viewpoint, it makes sense to me that if syphilis, which is a spirochete, can have chronic forms (and we know it can), then why can't Lyme disease have a chronic form? I'll leave this subject to others much more knowledgeable than myself.

ANESTHESIA AND CFS/FM

Many patients need to have operations for other reasons, such as appendicitis, hysterectomy, etc. When a general anesthetic is needed, I suggest asking for an anesthetic consult before the surgery to talk to the anesthetist about your particular situation and medications. Most CFS patients need extra IV fluids to

Table 1. Antidepressants (generics are shown in regular type, brand names in italics).

<p>Tricyclics (TCAs) Examples: Amitriptyline hydrochloride (<i>Elavil, Endep</i>), Doxepin (<i>Sinequan, Adapin</i>), Nortriptyline (<i>Pamelor, Aventyl</i>). Clinical uses for CFS/FM patients: pain relief, sleep disturbances, irritable bowel syndrome, temporomandibular joint syndrome, chronic low back pain, and the prevention of recurrent tension-type headaches. Possible side effects: increased appetite, constipation, difficulty concentrating, dizziness, daytime drowsiness, dry mouth, headache, nausea, sleep disturbances, tiredness, unpleasant taste, urinary retention, weakness, weight gain.</p>
<p>Selective Serotonin Reuptake Inhibitors (SSRIs) Examples: Fluoxetine (<i>Prozac</i>), Sertraline (<i>Zoloft</i>), Paroxetine (<i>Paxil</i>). Clinical uses for CFS/FM patients: mood disorders and the prevention of recurrent tension-type headaches; for individuals who cannot tolerate the side-effects of TCAs. Possible side effects: insomnia or difficulty sleeping, dry mouth, headache, decreased sexual drive or ability, dizziness, diarrhea or constipation, weight gain.</p>
<p>Dual Reuptake Inhibitors (DRIs) Examples: Venlafaxine (<i>Effexor</i>), Milnacipran (<i>Ixel</i>), Duloxetine (<i>Cymbalta</i>). Clinical uses for CFS/FM patients: the prevention of migraines and tension-type headaches and treatment of multiple symptoms in FM patients such as pain, fatigue, mood, and sleep. Possible side effects: increased blood pressure, anorexia, constipation, decreased strength, dizziness, drowsiness, dry mouth, ejaculation problems, impotence, nervousness, sweating.</p>
<p>Norepinephrine (Noradrenaline) Reuptake Inhibitors (NRIs) Examples: Reboxetine (<i>Edronax, Vestra</i>). Clinical uses for CFS/FM patients: pain and fatigue found in FM sufferers. Possible side effects: dry mouth, constipation, impotence, insomnia, increased sweating, rapid heart beat, urinary retention, vertigo.</p>

Table 3 (continued).

(Note: withdrawal symptoms - 48 hrs. rather than 12-20 hrs. as above)

Narcotics
Examples: Codeine (usually combined with Tylenol), Hydrocodone with acetaminophen (*Percocet, Dolacet, Hydrocet, Lorcet, Lortab, Vicodin*), Oxycodone (*OxyContin, Roxicodone*), Meperidine (*Demerol*), Morphine (*Astramorph PF, Duramorph, Infumorph, Kadlan, MS Contin, Hydromorph Contin, Oramorph SR, Roxanol, Roxanol Rescudose*), Propoxyphene hydrochloride (*Darvon, PC-Cap, Wygesic*), Fentanyl (Duragesic patch).
Clinical uses for CFS/FM patients: pain relief.
Possible side effects: constipation, dependency, dizziness, drowsiness, itching, tolerance, nausea, weakness, vomiting; at very high doses, respiratory depression and death. ↙

which is why withdrawal is dangerous if not prescribed in time

Table 4. Benzodiazepines/sleep medications.

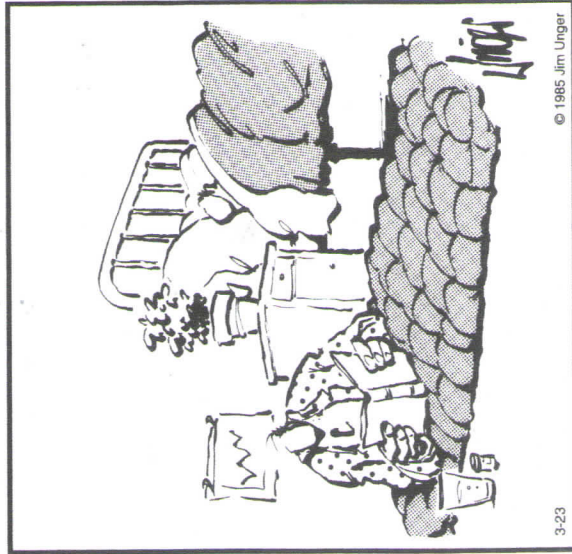
Examples: Clonazepam (*Klonopin*), Diazepam (*Valium*), Lorazepam (*Ativan*), Nitrazepam (*Mogadon*); Non-benzodiazepine hypnotics: Zaleplon (*Sonata*), Zolpidem (*Stullnoct*), Zopiclone (*Imovane*), Trazodone (*Desyrel*).
Clinical uses for CFS/FM patients: anxiety, insomnia, fatigue.
Possible side effects: addiction, aggression, confusion, dependence, drowsiness, enhanced effects of alcohol, morning "hang-over," light-headedness, memory loss, tolerance.

Table 5. CNS stimulants.

Examples: Methylphenidate (*Ritalin, Concerta, Methylin*), Dexamphetamine (*Dexedrine, Adderall*), Modafinil (*Provigil*).
Clinical uses for CFS/FM patients: to increase energy and alertness.
Possible side effects: addiction, anorexia, anxiety, dizziness, dry mouth, headache, irritability, nausea, nervousness, tolerance, worsening of sleep disorder.

Chronic fatigue syndrome and fibromyalgia patients often may be so ill that they can no longer carry out their normal occupations, and the effect can be devastating on the individuals and their families. People of all ages, educational backgrounds, and social standings, and of both genders, have been struck by these illnesses to such an extent that they can no longer work. Besides the impact on the individual's self-esteem, mental health, and familial relationships, the cold, hard economic reality also comes into play. An individual who is too ill to work can suffer from a significant reduction in income, lifestyle, and the ability to obtain much-needed medical care. Unfortunately, when individuals with CFS/FM are at their worst, they are then forced into hostile interactions with different income replacement systems, a stressor they are not often equipped to deal with. Fatigue, pain, and associated cognitive difficulties reduce the individual's abil-

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"Twelve years I've been paying
into that medical plan."

ity to deal with the administrative systems they desperately need to access when forced to leave an occupation. The main focus of this chapter will be the utilization of the legal system in an effort to secure financial security. However, some patients may use the advice to secure a working environment accommodated to their particular needs.

Many government agencies and almost all private insurers seem rather skeptical about the origins and impact of CFS/FM. The questions of whether the illness actually exists, and whether its symptoms are disabling, both in general and in specific cases, are often disputed. Agencies and insurers often reject claims for income replacement made by CFS/FM patients out of hand. This sets up the CFS/FM patient for a conflict, at the time when they have the least amount of resources, financial and personal, to carry out this fight. Finding and retaining appropriate legal assistance at this point can be crucial to your success or failure to maintain economic stability over what may be a very long and painful illness.

WHEN YOU NEED A LAWYER

When attempting to replace your income, a lawyer is usually not required for the initial application process either to a government plan or private insurer. Unless the claim forms are particularly complex or require the signature of a commissioner or a notary, there is no need to engage a lawyer for the initial preparation and delivery of paperwork to the insurer. To be frank, nobody knows the facts of your medical condition and personal life like you do, and a lawyer can add little to this part of the process. Assuming you are able to complete the forms on your own and your doctor is cooperative in providing the normally requested medical analysis at the opening of the file, retaining a lawyer for the initial application may simply be a waste of your precious funds.

A lawyer becomes important when the government agency or the insurer has refused your claim. Once they have indicated in writing that they are not willing to pay your claim, the situa-

cannot be an advocate for you if you cannot give him effective, clear-headed direction.

DISABILITY COVERAGE

It is important that you canvass all types of coverage available to help replace your income for the time you are going to be off work. There are often a number of systems available to assist you in any jurisdiction, including government agencies and programs, work disability insurance plans, and private disability insurance plans. While it is impossible to cover the details of each jurisdiction in a book of this nature, you need to be incredibly thorough in asking questions and making inquiries of all the relevant government agencies, your employer, and any insurer that you have had dealings with over the years. As an example, an individual in Ontario may have coverage available to them while they are disabled from any of the following sources, and perhaps more;

- Canada Pension Plan Disability Benefits
- Ontario Disability Support Plan
- Ontario Works Program
- Group Disability Insurance
- Private Disability Insurance
- Credit Disability Insurance
- Mortgage Disability Insurance
- Union or Fraternal Organization Insurance
- Alumni Insurance through University

You must be extremely thorough in canvassing all of these areas so you can ensure that the economic impact on yourself and your family will be the minimum possible while you are off work and that you are receiving all the benefits to which you are entitled under the various plans and policies.

Types of Disability Policies

There are many types of disability policies available to individuals. There are group policies, private policies, taxable policies,

and nontaxable policies. Many of them have a series of different definitions to deal with including questions about what constitutes a disability and what constitutes regular medical care. However, for the purposes of a doctor trying to help a patient deal with her disability insurer or an insured making an application, most of these distinctions are irrelevant. The only substantial concern for medical practitioners is whether the policy calls for a definition of disability based on "own occupation" or one based on "any occupation." The letter from the insurer asking for a report or an opinion should set out which of the two "occupations" is being addressed. In the event the insurer has not provided your treatment provider with information, you can request it from your insurer before they deliver their opinion. As you will see from the remaining discussion, the border between these two definitions has substantial overlap that will often allow your doctor to write an effective opinion even without knowing which type of policy is in place.

"Own Occupation" Policies

If the insured has an "own occupation" policy, he is entitled to benefits so long as he is unable to resume his regular occupation. Usually, this refers to the occupation the insured was engaged in at the time he became disabled. Total disability does not require complete helplessness, so the insured can collect benefits if he is "unable to perform all the substantial and material acts required in his usual occupations."

The insured is disabled if a reasonable person would recognize that he shouldn't work. Sometimes the insured is capable of carrying out the tasks which make up his job, but his performance is hindered by pain, fatigue, or medication. In other cases, medical advice or common sense makes it necessary to cease work in order to effect a cure or prolong the insured's life. Pain alone is not a disabling condition, but there are cases in which extreme or persistent pain makes it impossible for the insured to continue working.

(i.e. acting profession is extremely - mostly 14 hr. day - early, long and / or late hours)

The courts have recognized that some jobs require much greater precision and consistency than others. While impaired performances may be tolerable in some occupations, in others, even a small error can have unacceptable consequences, and an individual with a minor disability will be incapable of performing adequately. Thus, a group home worker with whiplash was held to be totally disabled because episodes of disorientation had resulted in two mistakes in dispensing medications to residents. Many other high precision/low error-tolerance occupations can be easily called to mind.

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C. Cicciolo
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Stress
Car - 2005
No papers

Often the insured has recovered partially and has begun to assume a role in her business, performing at least some of the tasks of her former occupation. At what point she is able to perform "all the substantial and material acts" which make up that occupation is a question of degree, but the courts tend to be lenient toward the insured. This is especially so where the claimant is self-employed or operates her own business. The courts don't expect the claimant to shut down her business because of an illness or injury. The fact that the insured goes to her usual place of business and does what she can or works through pain in order to keep the business going does not, by itself, establish that she is no longer disabled.

Procedure &

The courts have found, based on this logic, that a restaurant manager was considered to be disabled although he could complete his paperwork and a carpenter could be disabled even though he was able to supervise the renovation of his home. In another case, a businessman was held to be disabled despite the fact that he had arranged financing for his enterprise and completed some documentation.

"Any Occupation" Policies

A typical employer's group insurance policy provides the disabled employee with own occupation benefits for a period of one to three years, followed by a period of long-term disability coverage on an "any occupation" basis. The patient will continue to be

entitled to benefits during the "any occupation" period so long as he is prevented from engaging in work for which he is "reasonably suited by training, education, or experience" or work that is suited to his "skill and ability" or some other similar phrase.

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The transition from own occupation to any occupation coverage is a key moment in the life of a disability claim. Most insurers will take an aggressive approach to the claim when it reaches this point. They will ask for an update from the claimant's treating physicians, and they may request specialists' reports. The insurer may also exercise their right to have their own physician conduct an examination of the insured, and if they haven't done so already, consult experts in rehabilitation regarding alternative occupations.

A commensurate alternative occupation must be something that is comparable to the insured's former line of work in terms of status and potential earnings. The proposed occupation must be something for which the insured is qualified by virtue of his schooling and work experience.

The proposed job must require some sort of real application or effort on the part of the insured, and a position that "involves the performing of practically no work" will not be considered adequate. In one case, the insured obtained an appointment as postmaster in a small town, but virtually all of the work was done by employees and family members, and the court concluded that the appointment was an occupation in name only.

Remuneration

Often the earning potential of an alternative occupation is less than that of the insured's former work. The proposed job must be "reasonably comparable" to the insured's previous work "in status and reward," but the pay level need not match the income which the insured is accustomed to receiving. A disparity between the income of the two occupations is one factor the court will consider when deciding whether the new occupation is suited to the claimant. The adequacy of the remuneration is a question of

degree, and there is no clear rule establishing a point where the discrepancy between the old income and the new is unacceptable.

Nature and Status of the Work

The courts recognize that an alternative occupation must be consistent with the insured's personality and background. Thus the tastes and interests of the insured, as well as the nature and status of the previous work, are important factors. The courts are reluctant to accept that an individual can retrain for work that involves a social context and workplace environment that is foreign to them, particularly when the individual is an older worker or someone who has been involved in a particular line of work for a long time.

There are many cases in which courts have refused to compel people who are accustomed to physical labor or outdoor work to switch to clerical duties or light work in a store or office. Similarly, courts have often rejected the suggestion that professionals, managers, and executives should take on work which involves a reduction in social status or even a new specialty within the same profession.

Where the claimant is a young person with no long-standing commitment to a particular type of employment, judges are more likely to conclude that retraining is appropriate.

Does Part-Time Work Qualify?

Whether only being able to work part time qualifies as being "totally disabled" is more of a legal question than a medical one. However, there have been a number of cases in which the court has found the ability to work only part time still leaves one in a state of "total disability." Therefore, when your doctor writes your reports to insurance companies, he or she should not foreclose the possibility of disability simply because an individual who has returned to work part time may not appear to be "totally disabled" from a medical sense. They may well be in a legal sense. A reasonable guide on the issue of disability (although the cases

move all over the map on this particular issue) is that if an individual is making only 65 to 70 percent of the amount they made in their occupation previously, then that person may not be "totally disabled," although they may qualify under some policies as being "residually disabled."

The most effective route for the treating practitioner writing a medical report on this issue would be to quantify as precisely as possible the amount of part-time work being done. Any specifics should be passed on to both the insurer and the counsel to assist them in making an accurate determination of their rights under the policy. Since the insurers appear to inherently distrust people who make claims, independent verification of this information from the treating practitioner will often help arrive at a just conclusion.

In the modern environment of CFS/FM, multiple chemical sensitivity, and other so-called functional somatic syndromes, variability of symptoms is an important factor. The courts have ruled quite clearly that an individual who has variable symptoms and cannot commit to a regular scheduled employment due to those symptoms is totally disabled. The courts have taken a much more "real world" approach than the insurers. In the real world, if an individual cannot commit to some sort of work schedule, it is almost impossible to obtain employment. The case law is clear that the variability of symptoms and inability to commit to a regular working schedule can completely disable an individual on their own, even though the symptoms may allow for part-time work or work at times when the individual is in a period of remission or on a "good day."

Objective Versus Subjective Symptoms

Many insurers will ask the doctors only to report "objective" symptoms of illness. This is inappropriate and probably a bad faith step. I have reviewed a significant number of long-term disability contracts, and I have yet to see one which defines disability in terms of "objective" symptoms. There are a number of cases

most cases

LEGAL
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