ME/CFS Management
An Approach to Finding Physician Care

One of the greatest challenges and sources of frustration for ME/CFS patients and their families is the difficulty in finding a physician or team of physicians who can competently support their medical needs. Even though there have been significant advances in our understanding of ME/CFS in recent years, there is still a great deal of ignorance among the medical community about ME/CFS. Most physicians still do not know how to diagnose or treat chronic fatigue syndrome. While many, if not most, physicians now recognize and believe that ME/CFS is a real and debilitating medical illness, the diagnosis of ME/CFS sometimes still continues to carry a social stigma. Compassionate and competent medical care for ME/CFS is often very difficult to find.

ME/CFS is an extremely complex illness with multi-system involvement. Any effective and comprehensive ME/CFS treatment strategy encompasses a broad range of medical disciplines. The cause(s) of ME/CFS remains unknown. There is no medical cure for ME/CFS. There have been few controlled clinical trials focused on the treatment of ME/CFS. Nevertheless, in many cases, ME/CFS can be treated in a manner that will substantially improve the patient’s quality of life.

For a comprehensive guide to the diagnosis and treatment of ME/CFS, please refer to (i) the 2005 Myalgic Encephalomyelitis / Chronic Fatigue Syndrome: A Clinical Case Definition and Guidelines for Medical Practitioners – An Overview of the Canadian Consensus Document (http://fm-ME/CFS.ca/me_overview.pdf), (ii) the 2003 Canadian Myalgic Encephalomyelitis / Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols (http://fm-ME/CFS.ca/ME/CFS-Protocol.pdf) and (iii) the 2002 New Jersey Consensus Manual for the Primary Care and Management of Chronic Fatigue Syndrome (http://www.njME/CFSa.org/Manual.pdf). Even though these documents can be used as a guide to the diagnosis and treatment of ME/CFS, patients still need to find physicians who can help them to plan and implement clinical strategies. We strongly recommend that any ME/CFS treatment plan be formulated only with the advice of appropriate, knowledgeable physicians.

ME/CFS Primary Care Physicians

The first goal for any ME/CFS patient is to find a primary care physician – usually an internist, family practitioner or pediatrician – who is experienced and knowledgeable about the care of ME/CFS patients. This is not an easy task since there are many more ME/CFS patients than there are primary care physicians who are skilled in the art of caring for ME/CFS patients. Furthermore, the geographic distribution of these ME/CFS physicians is not always suitable to meet the ongoing needs of the ME/CFS patient.

Practically speaking, the ME/CFS patient may not always be able to locate a geographically suitable, primary care physician who is knowledgeable about ME/CFS. In such case, the ME/CFS patient would alternatively need to find a primary care...
physician who believes in a medical basis for ME/CFS, can provide the ME/CFS patient with compassionate care and can effectively partner with the patient to provide the best possible care. In looking for a primary care physician to help manage the patient’s ME/CFS, the patient needs to be upfront and clear with the physician about his/her needs and interview the physician regarding their belief system about ME/CFS in order to minimize potentially frustrating interactions with the health care system. It is certainly preferable for a patient to have a primary care ME/CFS physician who is knowledgeable and experienced in the care of ME/CFS patients. However, even though such a physician may not always be available, a ME/CFS patient can still obtain effective care for their ME/CFS if they are able to find a compassionate primary care physician who is willing to partner with the patient to treat the patient’s ME/CFS symptoms. In any event, the primary care physician – whether or not they have a special expertise with ME/CFS – should be willing to refer the patient to the right specialists who can further assist in the diagnosis and treatment of the patient.

Physician Specialists

The second goal for any ME/CFS patient is to find specialists who can assist the primary care ME/CFS physician with specific aspects of the pathology of each ME/CFS patient. Since individual ME/CFS patients may differ in their clinical presentation, any effective therapeutic plan must be tailored to the unique needs of the patient. Just as ME/CFS patients may have difficulty finding a suitable primary care physician, a suitable primary care physician may have difficulty finding the right kind of specialists near the home of the ME/CFS patient for consultation and referral.

Nonetheless, there are certain general principles that are applicable to all ME/CFS patients. If the root cause of ME/CFS can determined (e.g. www.hhv-6foundation.org, www.aldf.com, www.ihmf.org), then the ME/CFS patient and his/her physicians should address the root cause as early in the clinical course of the patient’s illness as possible. There are many possible root causes of ME/CFS (i.e. infectious, environmental, genetic or physical triggers) that may interfere with the normal functioning of the patient’s immune system and central nervous system. A full discussion of the possible root causes of ME/CFS is beyond the scope of this summary. Please see the documents listed in the third paragraph above for a more detailed discussion of possible root causes. In most cases, the root cause of the patient’s ME/CFS will not be determined. Care of the ME/CFS patient will then be focused on the careful diagnosis of the patient’s symptom presentation and alleviation of these symptoms. Appropriate treatment of ME/CFS symptoms can often result in a substantial improvement in the patient’s quality of life.

Sleep Abnormalities and Chronic Pain

The two symptoms that should be most aggressively treated are difficulties with restorative sleep and chronic pain. Chronic fatigue is usually more difficult to address, especially when it is the predominant symptom and when fragmented, dysrhythmic sleep patterns and chronic pain are lesser symptoms. However, effective treatment of sleep
abnormalities and effective control of chronic pain can often make a substantial difference secondarily in the patient’s level of fatigue.

The first specialist to whom all ME/CFS patients should be referred is a physician that is board certified in sleep medicine who practices as a staff physician at a certified sleep clinic (http://www.aasmnet.org/, http://www.sleepcenters.org/). A board certified sleep physician should be able to make an accurate diagnosis of the nature and severity of the patient’s sleep abnormality and to make appropriate treatment recommendations.

The other specialist to whom all ME/CFS patients should be referred is a physician who is experienced in diagnosing and treating chronic pain disorders and who also has some familiarity with ME/CFS. As there are many different types of physicians (http://www.painmed.org/) who as part of their practice may treat chronic pain, it is impossible to generalize about the speciality of the physician to whom the patient should be referred for chronic pain treatment. The patient’s primary care physician may decide to take the lead role in treating the patient’s chronic pain. Not infrequently, however, a primary care physician will not have the specialized expertise necessary for optimal management of the medications typically used in the treatment of chronic pain.

Alternatively, the patient’s chronic pain physician could be a psychiatrist with a specialty in psychopharmacology (http://www.psych.org/psych_pract/), a neurologist with a specialty in psychopharmacology (http://www.aan.com/professionals/), an anesthesiologist, a physiatrist, an internist or some other type of physician. The main goal is to adequately treat the patient’s chronic pain with a safe combination of medications and physical rehabilitation modalities.

A Unified Approach to Treating Sleep Abnormalities and Chronic Pain is Desirable

There are many different medications that can used to treat the sleep problems and chronic pain of ME/CFS patients. In many cases a particular medication may have a beneficial effect on both the patient’s sleep abnormality and chronic pain. It is a complex undertaking for a ME/CFS patient to find the right combination and coordination of physician care providers. A general recommendation is to try to simplify the patient’s treatment regimen and reduce the total number of doctors’ office visits as much as possible by having a single physician manage the patient’s medications for sleep abnormalities and chronic pain.

The sleep abnormalities and chronic pain of ME/CFS are often treated with medications that affect neurotransmitter levels and function of the central nervous system (CNS). Therefore, the ME/CFS patient is recommended to find a physician who is knowledgeable and comfortable using CNS medications and who has the experience of using these medications for many of his patients on a daily basis. CNS medications are often habit forming, and can often have untoward side effects or interactions with other medications.
Judicious use of CNS medications with small, careful, incremental changes over time tends to work best. While sleep abnormalities and chronic pain should be treated aggressively, the minimal effective medication level should be used. However, more often than not, sleep abnormalities and chronic pain are mistakenly under treated. ME/CFS patients and their physicians should not be afraid to use CNS medications, so long as prudent caution is used. A knowledgeable physician with an appropriate level of expertise in managing CNS medications should be making the judgments about medication types and doses in partnership with the patient. Finding an appropriate balance with the right combination of medications at appropriate dosages can be a tricky endeavor, especially since many ME/CFS patients tend to be sensitive to the effects of many medications. The right medication combination can only be determined when the patient is an active participant in consultation with the right physician team.

Neurologists or psychiatrists with expertise in psychopharmacology often have the most experience using medications that affect CNS function. However, not all neurologists or psychiatrists are uniquely skilled in the art of the long term management of CNS medications. If a patient can find a single neurologist or psychiatrist with special expertise in psychopharmacology to manage the patient’s CNS medications for treatment of sleep abnormalities and chronic pain, this would be a recommended approach. It is generally more important for the physician managing CNS medications to be more familiar with the use of these medications than they are with the complexities of ME/CFS. In depth knowledge of ME/CFS is desirable when managing CNS medications, but not always necessary.

**Fatigue**

The cause of fatigue in ME/CFS is poorly understood, but probably results from a combination of dysfunction of the central nervous system, the immune system, the neuroendocrine system and/or abnormalities of metabolic regulation.

**Autonomic Nervous System**

Another recommendation is for the ME/CFS patient to have an appropriate evaluation of the function of their autonomic nervous system. This is typically undertaken by a cardiologist specializing in cardiac electrophysiology with a particular interest in dysautonomias (http://www.ndrf.org/). Usually autonomic nervous system function will be evaluated with a tilt table test. Based on the results of this autonomic nervous system assessment, specific recommendations may be made by the cardiologist to the patient’s primary care physician.

**Irritable Bowel Syndrome and Interstitial Cystitis**

ME/CFS patients frequently suffer from irritable bowel syndrome (IBS) (http://en.wikipedia.org/wiki/Irritable_bowel_syndrome) and less frequently, but not uncommonly, suffer from interstitial cystitis (IC) (http://www.ichelp.com/). These conditions should be treated by the patient’s gastroenterologist (http://www.acg.gi.org/).
Effective treatment of the ME/CFS patient’s IBS or IC can result in a substantial improvement in the patient’s quality of life.

Infectious Diseases and Immunology

Patients may also benefit from a work up of their immune system with special attention to possible infectious triggers. While most infectious disease specialists and immunologists don’t typically manage ME/CFS patients on an ongoing basis, some do. Even if the infectious disease or immunology specialist does not typically manage ME/CFS patients, they may be able to order useful, specialized diagnostic testing that may offer insights into the patient’s condition.

A detailed discussion of infectious disease triggers of ME/CFS is beyond the scope of this presentation; however, recently much new interest has been generated on the possible role of herpesviruses as a trigger or perpetuating factor in ME/CFS. Determination of the precise role of herpesviruses in ME/CFS still requires much new research, but as newer, more sensitive and specific diagnostic tests are developed, the role of herpesviruses in ME/CFS will become better defined.

If an infectious trigger is found, the potential risks and benefits of treatment should be discussed with the infectious disease specialist, so that an appropriate decision about treatment or non-treatment can be made. Unfortunately, many more well-designed, placebo controlled, clinical studies will necessarily have to be performed in the future before uniform clinical guidelines for the treatment of various infectious triggers can be established with greater clarity.

Due to the complexities of the human immune system and our limited understanding of these complexities, primary treatment of the immunologic abnormalities typically found in ME/CFS patients is difficult at best. Although there are a number of immunomodulatory and antiviral therapies that have been proposed for ME/CFS, none of these therapies have been proven to be effective with carefully designed, placebo controlled, clinical trials. A patient’s decision to “experiment” with any of these therapies should only be undertaken after discussion of the potential benefits and risks of these therapies with the patient’s primary care physician and consulting specialists. ME/CFS patients should be mindful that no ME/CFS therapies are without potential risks; however, anecdotal evidence suggests that certain immune and antiviral therapies may have substantial benefits for a subset of ME/CFS patients.

Alternative Therapies

There are a myriad of different alternative modalities and nutritional supplements that have been proposed as effective in the treatment of ME/CFS. Some of these therapeutic
strategies may have modest benefits as an adjunct to the overall treatment plan for the ME/CFS patient, but they should not be regarded as a cure. A patient’s decision to pursue any of these therapies should only be undertaken after discussion of the potential benefits and risks of these therapies with the patient’s primary care physician and consulting specialists. ME/CFS patients should be mindful that no ME/CFS therapies are without potential risks. Generally speaking, in the absence of definitive evidence as to the benefit of a particular alternative treatment or supplement that the patient has tried, the patient would be well advised to try to simplify his/her treatment plan to the extent possible.

Psychological Support

ME/CFS is not primarily a psychological illness. However, many patients and their families may benefit from general, supportive psychological interventions to help them cope with the emotional effects of such a devastating, poorly understood chronic illness and to help guide them through their efforts at rehabilitation and adaptation. Counseling and support presented in a non-judgmental manner should typically be offered to the ME/CFS patient, the patient’s family and the patient’s spouse.

Severe clinical depression that may sometimes accompany ME/CFS should be treated aggressively with particular attention to the possibility of suicide.

Activity and Exercise

The line between what is exercise and what is activity is hard to define and can be easily misinterpreted by patients, their caregivers and health care professionals. There are many ME/CFS patients who have such severe activity limitations that exercise or even minimal activity should not be recommended because it can be harmful. These ME/CFS patients, especially those more severely affected, may be hurt more by doing too much than by doing too little. However, there are also many ME/CFS patients for whom a carefully controlled exercise program can be a very useful adjunctive modality to help the patient maximize their ability to function at a higher level within the confines of their disability.

ME/CFS is a chronic illness with a clinical course that more often than not evolves over many years. Careful “activity” management will help prevent the patient’s tendency to overdo it with the possible result of increased severity of symptoms and an exacerbation of the patient’s condition. While some ME/CFS patients may temporarily from time to time have to resort to complete bed rest, it is in the patient’s interest to minimize rest periods during the day to the extent possible. However, it is also not in the patient’s interest to push through periods of extreme fatigue and rest periods are inevitable. Exceeding a patient’s energy limits as defined on an individual case by case basis by the severity of the patient’s illness can lead to an exacerbation of the patient’s symptoms that can last for several days or much longer if the patient exceeds his or her limits on a regular, ongoing basis or to an extreme degree.
For more severely affected patients, rest periods may be a daily occurrence, or sometimes a several time a day or majority of the day occurrence. Resting more than is necessary can harm the patient since it may result in progressive muscle de-conditioning and increased levels of fatigue. In summary, “activity” management is an inexact science. Especially in more severely ill ME/CFS patients, there is often a very fine line between too much and too little activity. The ME/CFS patient must closely monitor his or her own activity levels according to the subjective evaluation of his or her own symptoms. Gentle encouragement by family members for the ME/CFS patient to increase their activity levels can be helpful in motivating the patient. However, it is very important for family members to be cognizant of the fact that overzealous encouragement can be counterproductive and detrimental to the patient’s condition.

Recognition of a patient’s inherent activity limitations coupled with a gentle exercise program that is individually tailored to the patient’s capabilities can be a beneficial therapeutic intervention, even for some of the more severely affected ME/CFS patients. However, exercise is not a cure for ME/CFS and does not modify the underlying illness process. It is an important modality that can help the patient to better adapt to his or her condition and improve the patient’s overall capacity for activity within the scope of the severity of the patient’s illness. The focus of any exercise program for a ME/CFS patient should be on regularity, not quantity, of exercise.

During the course of any therapeutic exercise rehabilitation program for an ME/CFS patient, a patient’s exercise tolerance limits may be increased by very modest amounts if symptoms do not re-emerge. Challenging a patient’s exercise tolerance limits too much carries the risk of causing an exacerbation of the patient’s condition. Since ME/CFS patients often function dangerously close to their energy limits, an exercise program may sometimes involve a prioritization or trade-off between the patient’s limited energy resources that are required to complete the exercise protocol and the energy resources that may be required for the patient to perform other necessary activities of daily living.

Increasing the quantity of exercise for an individual patient should progress at an extremely slow, gradual pace over long periods of time and only as tolerated by the patient. Even with an appropriately titrated exercise program, the patient’s ceiling level of exercise will still likely be considerably limited. For many severely ill ME/CFS patients, an exercise program must be initiated with only a very few minutes of very light exercise per day. In many cases the patient may only be able to start off with 5 minutes of very slow walking per day. The amount and intensity of exercise is not the critical determinant. The regularity of the exercise is. Exercise tones the autonomic nervous system function and the function of a ME/CFS patient’s autonomic nervous system is frequently impaired.

In addition to activity management, pacing and exercise programs, other physical interventions, such as massage, stretching or gentle yoga, can also be helpful as long as the patient is cautious and careful to stay within their own activity and energy limits. Just as exercise may be either beneficial or harmful to the patient depending on how it is
administered, massage, stretching and yoga also has the potential to be beneficial to the patient if prudent judgment is used or harmful if the intensity of these physical modalities exceeds the patient’s limited capacity to engage in these activities.

Even if a patient was theoretically able to totally eliminate the root cause of his/her ME/CFS at a particular moment in time, the physiologic impairments resulting from such having a chronic illness over long periods of time would take a considerable amount of time to heal. Expectations about rehabilitation and recovery must be tempered within the framework of this perspective. Generally speaking, if a patient has been severely ill for a longer period of time, this patient’s pace of rehabilitation will be more gradual and more prolonged than more moderately affected patients. In many cases, rehabilitation will be only partial and the patient may never fully recover to their formal level of functioning. However, some ME/CFS patients do recover over time to their pre-illness baseline and many ME/CFS patients do recover substantially, even if incompletely, over many years. Some patients recover to a large extent even after being ill with ME/CFS for many years. In any case, the timing of any individual ME/CFS patient’s recovery is largely unpredictable.