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One of the most frequently asked questions by people who have, or think they might have, the Chronic Fatigue Syndrome/Chronic Fatigue and Immune Dysfunction Syndrome/Myalgic Encephalopathy (CFS/CFIDS/ME) or Fibromyalgia (FM) is who are the "experts" working with these illnesses in their area. The answer is these are "few and far between" and scattered around the country. There are doctors who are very knowledgeable and see patients in all-inclusive centers dedicated to these particular illnesses. However, using these may require considerable travel, and good insurance coverage, as well as sufficient financial means by which to absorb the cost of travel and patient balances on services and treatments.

There are centers in many states that have combined a variety of practitioners and offer a range of healthcare services, usually a blend of traditional and alternative medicine. These type of centers work with many chronic conditions and might be good options for a number of patients. However, these centers tend to accept few insurance plans.

The best suggestion for patients is not to lose hope, but learn how to take advantage of the health care that is available to them—according to their insurance and within their financial means. It is still possible to relieve symptoms, reduce exacerbations and improve overall function without going to the "experts".

### **Finding a Health Care Provider**

Most of us with CFS/CFIDS/ME or FM can appreciate that finding a caring and capable doctor

can be half the battle. This can be quite a frustrating and disappointing process. Patients will gain more (more help, less frustration) if they set realistic expectations and employ certain strategies to make the most of what is available to them. It is also important for patients to become aware about some of the factors driving the current problems in healthcare.

Many states (Massachusetts, in particular) are suffering a significant shortage of primary care physicians mainly due to fewer medical students going into primary care, being paid a much lower income in this field and many doctors becoming overwhelmed by tighter schedules and higher patient quotas imposed on them. As a result, many established doctors are leaving this field and some have set up private practices which operate on annual cash retainers (i.e. "boutique" or "concierge" medicine).

Many chronically ill people are often covered under Medicare provisions and/or Medicaid (a medical benefits program administered by states and subsidized by the federal government). Be aware that Medicaid is not accepted by all doctors due to very low reimbursement rates being reported. So, what we all are left with is a healthcare system which is certainly not fair nor easy. Thus it becomes all the more important for patients to learn how to make the most of what is available to them.

Primary care physicians (PCPs), most often internists, but who can also be general or family practitioners or doctors who specialize in geriatric or pediatric care, are usually the first point of consultation. Patients, especially those who have developed chronic and multiple health problems, really need someone to help oversee things and guide them along, especially when they are too sick to do so on their own. A capable, open-minded PCP can be quite instrumental in helping patients connect with other doctors (even if they themselves are not highly knowledgeable about CFS/CFIDS/ME and FM) who can evaluate, order appropriate tests, and recommend treatments to minimize symptoms, reduce exacerbations and improve daily function.

It is highly unlikely that any single healthcare provider is able to adequately address all of medical issues found in CFS/CFIDS/ME or FM. These illnesses are complicated, affect many body systems, and respond best to a multi-pronged treatment approach. Specialists can get the ball rolling but, by and large, they do not get involved with ongoing care. Therefore, this highlights the need and benefit of finding a good PCP and learning how to work with him or her. There are things patients should look for in primary care physicians and some things which are reasonable to expect from them as well as ways for patients to make the best use of time spent with their doctor.

### **Tips on how to get the most out of a doctor's visit**

Finding a primary care physician has become a challenge for many patients around the country and this is becoming a frequent topic reviewed in magazines. Even aside from someone seeking medical care for CFS/CFIDS/ME or FM, time allotted for appointments with physicians is shrinking. So patients, like it or not, must prepare for them as carefully and thoroughly as possible. Many, but not all, of the tips and recommendations listed below are those provided by Dr. Lucinda Bateman in a workshop at the 2007 International Association of Chronic Fatigue Syndrome/Myalgic Encephalopathy (IACFS/ME) Conference.

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Primary care physicians/providers should be personable, open-minded, accessible and up-to-date. As patients, many of us realize that finding someone who satisfies even these four qualities might be a challenge. One important thing to remember is that this will be the doctor with whom patients will likely have the most contact and therefore, this needs to be someone with whom they can comfortably communicate.

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Many patients will try to stay with their current PCP but might find as their needs change, or their condition becomes more complicated, that their doctor does not adequately understand the scope of their illness. If their doctor is at least open-minded and will accept information about the illnesses, then it is still possible to work with him/her. However, if patients find their doctor is not listening to them, not believing in their symptoms or dismissing them in some way, or becoming apathetic or rude towards them, then they will need to find someone else.

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Try to get more information about new PCPs before making the switch (i.e. before actual transfer of medical records and designating him or her on an insurance plan). Some practices, at least in the past, were agreeable in having patients meet and have a short, general discussion with a given doctor about their knowledge and working experience with CFS/CFIDS/ME or FM (often referred to as "meet and greet" appointments). Another option

might be to call and review the same information with the office manager.

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The role, skill and scope of the primary care provider is another important issue to understand. It is reasonable for patients to expect that their PCP will provide them with urgent care (assess an urgent problem or direct patients for appropriate care), help them receive a diagnosis for any given problem (whether the PCP is able to do so on his/her own or needs to refer patients to a specialist for evaluation), help to manage chronic symptoms or conditions, and check that preventative testing or care is getting done. From a patient's experience, this is how primary care should be ideally provided. But realistically, there will be times when some PCPs will prefer to turn over certain aspects of the illness to other doctors. One important area of debate is who is best able, or willing, to take on pain management.

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Plan ahead and schedule follow-up appointments while at the doctor's office. Arrive to appointments on time or early (the extra time can help people gather their thoughts and recover from travel to the office). The goal is not to waste any of the consultation time.

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Prepare as much relevant information as possible ahead of time for an upcoming consultation, especially by having a list of current medications readily available, completing forms at home (ask if these can be mailed or transmitted ahead of time), and identifying which symptoms/problems will need to be addressed at this appointment.

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Keep a personal journal (whether in a notebook, in the blocks of a large calendar, or on the computer) to track symptoms, medications, reactions to medications and/or what might trigger some symptoms. This tool can help patients not to overlook anything at the visit and maximize time with the doctor.

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Once at the office, limit the conversation on niceties and unrelated issues to a minimum. Also, don't waste time with the doctor on things that s/he would likely not be in charge of, such as billing questions, bad parking, or some other non-medical matter.

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Go to the appointment with the above information written down, but keep it short. Perhaps go in with only an outline of these concerns and problems. Keep as much information as you want for your personal use, but it is better to condense this information for a doctor's visit.

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Consider using other ways to quickly and effectively communicate symptoms with the doctor—create a small chart of primary, recurring symptoms (i.e. sleep, mood, pain, fatigue) and rank these from 1 to 10, or create a pain diagram (using an image of a body, front and back) and highlight and note areas of pain. These can also be effective tools by which to monitor improvement or changes. A word of caution from a patient's perspective—don't go overboard with this sort of thing and recognize that some doctors may totally misinterpret these efforts by thinking patients are far more functional than they are just by being able to compile this information, or viewing them as becoming overly obsessed about their illness (by the attention they are giving it).

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Try to coordinate presentation of symptoms to how most doctors handle their office visits—they follow an approach called SOAP—**subjective** (this is part of patient-reported problems), **objective**

(data captured/ reviewed by the doctor),

**assessment**

t, and

**plan**

. Therefore, prioritize and bring up symptoms and concerns at the beginning of the appointment.

Above all, don't hold out on bringing up an important problem until the end of the visit—even if there is some hesitation or embarrassment about it.

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If the doctor starts to ask questions before all symptoms can be brought up, then politely remind him or her that there is more information to be shared on that problem, or that there are several other problems to cover at this appointment. If there will be many problems and concerns to be reviewed, be sure to schedule an extended appointment.

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Know your insurance plan, and what it will cover or not, ahead of time. Remind the doctor about plan limits or high co-pays, especially when certain tests or medications are being proposed.

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Know your medications—learn their proper names, dosage, how they are to be taken and their general purpose. When listing these, organize them by *purpose*, because this can help the doctor easily see the conditions for which patients are being treated and what is being used. Include any supplements or herbal medicines and provide all healthcare providers with the same list. Be sure to review risks and benefits of each medication, as well as interactions. Medications and relevant information (like side effects) used in the past should be listed separately from those currently taken on a regular basis.

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Identify and know your conditions and their status. For instance, if someone has sleep apnea, note the date of the last sleep study and whether any equipment is being used as part of treatment. If someone has a thyroid problem, note the last relevant test results and what medications are being used to control this problem, and so on.

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Know, keep track of, and arrange for your own basic preventative screenings and tests (i.e. GYN exams, mammograms, or prostate exams). It is also recommended that patients be aware of when periodic lab tests should be ordered while on certain medications.

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Ask for and receive a copy of all lab tests done and keep in a file folder or binder. If you can scan them and keep copies on the computer, that is helpful as well.

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Know what the general criteria are for CFS/CFIDS/ME or FM and how you meet the case definition for these illnesses. The criteria to evaluate and diagnose these illnesses are recognized by the U.S. Centers for Disease Control & Prevention (CDC), regardless of some criticisms and ambiguities surrounding the CFS 1994 definition. (The 1988 CFS definition is more stringent and matches more closely what patients and many researchers recognize as ME). This is something patients can use if, or when, some doctors might say they do not know anything about CFS/CFIDS/ME or FM, or claim the illnesses don't exist. Consider printing this criteria and having them available in the event one ever needs to support their having these illnesses.

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Most patients find it may be very helpful or even necessary to bring a family member or a friend (complete appropriate HIPAA privacy forms first) when meeting with a specialist and/or when a lot of information needs to be exchanged. It can be very difficult to concentrate and absorb details when learning about a new medical problem. Also, ask for the doctor to write down the diagnosis, certain terminology that s/he used during the consultation, medications, and/or anything else relevant to this particular problem.

**What type of doctor is best for CFS/CFIDS/ME or for FM?**

To understand what type of doctor is best suited for CFS/CFIDS/ME and FM, it is helpful to consider how doctors might have learned about the diagnosis and treatment of these illnesses. Lack of time may prevent the most well-intentioned doctors from staying abreast of the most significant research information and clinical guidelines on many illnesses.

As mentioned earlier, the worldwide number of physicians (some of whom are also involved in research) who could be considered to have true expertise in the diagnosis and management of CFS/CFIDS/ME is very limited. Periodically, some medical journals will publish information about CFS/CFIDS/ME, like the *New England Journal of Medicine*, but the depth to which these articles go or the random aspects brought up about these illnesses can vary greatly.

The Centers for Disease Control & Prevention (CDC) in Atlanta, Georgia, has set up guidelines on the diagnosis and treatment of CFS/CFIDS at its website but these are not comprehensive. Their website provides limited comments regarding current research.

How many doctors have become informed about CFS/CFIDS/ME remains ambiguous and could greatly influence their understanding of the illnesses. Even the formal 1994 criteria and case definition devised by CDC researchers for evaluation and diagnosis of CFS/CFIDS/ME is now considered to be deeply flawed and there is a move to change it. Patients have had some success in getting diagnosed with CFS/CFIDS/ME by infectious disease specialists or neurologists, partially due to the type of abnormalities and dysfunction they might detect in various tests. Details about the two most widely used diagnostic procedures can be found in our [Diagnosis](#) section.

Individuals who have FM have been usually diagnosed by rheumatologists mainly because the standards for the classification of FM were created in 1990 by the American College of Rheumatology. Therefore, FM tends to be somewhat better recognized by doctors in this specialty, though there can be differences in their treatment approaches and the research or theories any given rheumatologist may follow.

Other specialties that might be working with FM (in more recent years) are physiatrists (as this is a branch of medicine that focuses on the patient's musculoskeletal system and spine, and uses physical therapy and some medications as primary treatments) and sometimes, pain management specialists (some are physiatrists, but usually they are anesthesiologists) can help with persistent, chronic pain. The CDC also has a summary on the diagnosis and treatment of FM but it is very limited. Criteria for the classification of FM is further detailed in our [Diagnosis](#) s



ection.

It is clear that doctors might learn the most about CFS/CFIDS/ME and FM through their patients. Patients with CFS/CFIDS/ME might want to tell their PCP about a two-hour course *Chronic Fatigue Syndrome: A Diagnostic and Management Challenge* co-sponsored by the CDC and the CFIDS Association of America. The trainers are Dr. Charles Lapp and Leonard Jason, Ph.D.—who are well-respected CFIDS researchers and clinicians. For further information see [For Health Care Providers](#)

### **Cheat Sheet for Doctor's visits**

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Make a list of your questions, then sort them in order of importance and ask only the top 3-4 questions. Brevity and time is of the essence.

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Write down the doctor's answers.

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If tests are being ordered at an independent lab, have the doctor write "copy to patient" on the script, so you can get a copy sent to you.

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Don't overload a doctor with all your symptoms. This will tend to shut him/her down.

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Bring pertinent information and test results from other doctors with you. Do not rely on the doctor's office faxing something. This saves time.

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Ask the doctor to make pertinent notes in your record (i.e., not sleeping well causing increased flu-like feeling, drowsiness during the daytime, etc.). Many times a doctor tunes this important information out and just simply skips it. Having this information in your record will also be very important for filing for disability.

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Ask for the longest appointment necessary to meet the number of important matters to be reviewed. Sometimes s/he will have a 40-minute time slot.

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Consider seeing your primary care physician more frequently, either monthly or bimonthly, when possible. It is easier to catch your PCP up on problems on an ongoing basis than once or twice a year.

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Try to keep a log of any medication reactions, good and/or negative, that you have. Don't trust your memory.

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*Do not accept abusive behavior from doctors.* Many patients feel they have no choice. But abuse—emotional or physical—is not acceptable behavior.

### **More resources**

[\*CFIDS Self-Care: The Basics\*](#)

[\*The CFIDS Initiation - A Primer for New Patients\*](#)

[\*On the Morbid Fascination with Psychiatric Morbidity\* by Dr. Alan Gurwitt](#)

[\*The Physical Basis of CFIDS\* by Dr. Anthony Komaroff](#)

[\*Using an Emergency Room\*](#)