

“Working with Your Health Care Provider” – A Mass. ME/CFS&FM Association Presentation -

A Follow-up Guide – Issues and Resources

Working with your health care provider presupposes you have a provider you can work with – *and* that you aren't seeing a provider that you cannot work with, or who is unwilling to work with you.

Finding a Knowledgeable Doctor or Other Provider –

The best place to start is to contact a local patient support group/patient organization and ask if they know of doctors in your area who treat your illness.

If your PCP refers you to another doctor for an evaluation of your illness, make sure you ask your doctor about the qualifications and knowledge of the provider you are referred to.

Both medical doctors and integrative physicians may be knowledgeable and capable of treating these illnesses – although their treatments may differ. Be wary of any physician who makes unreasonable claims for a particular treatment. Try to get information on treatments offered. Talk to a patient support group to help in learning about a provider. (*See a list of support groups nationally at the end of this piece. Also see ME/CFS doctor data bases also at the end.*)

Primary Care Physicians and Specialists

ME/CFS, fibromyalgia, Long-Covid, and post-Lyme patients all need a medical care doctor who can provide good primary care for the range of potential primary care issues.

They also need specialty physicians who are knowledgeable about these illnesses.

Many PCPs do not know much about these illnesses – but can provide excellent general medical care. As long as the PCP recognizes that the person is physically-ill and might have one of these illnesses, and who will refer them to a competent illness specialist, the individual may be satisfied with the PCP.

The PCP should be either somewhat knowledgeable about ME/CFS and/or FM -- or at least not be biased against the illnesses in terms of seeing them as

psychological or social in origin. The doctor should be understanding of the difficulties of chronic illness and hopefully be open to learning about the patient's illness.

No patient should stay with a provider, PCP, or specialist, who is not interested in or willing to make their best effort to help the patient – or who is outright dismissive or rude, and who does not recognize the person is ill -- and who psychologizes the illness. Some doctors are arrogant in their biases or ignorance. The best way of working with such a provider is to turn around and walk or run away and find a doctor who is qualified to help.

Doctors who are open and understanding, even if they are not knowledgeable, may be willing to read material that is not too long that the patient can bring to them -- either to help in diagnosis or once the diagnosis is made.

Besides an excellent PCP, most patients will need a provider who is knowledgeable and experienced with the overall evaluation and treatment of their illness. Also these illnesses may require various specialists for the different illness pathologies: including specialists in dysautonomia, infectious disease, sleep, pain, neurology, endocrinology, pulmonology, cardiology, physical rehabilitation, etc. It is critical that these specialists have knowledge of the underlying illness which they are in part addressing. Get referrals to specialists who are knowledgeable about ME/CFS, FM, long-Covid, or chronic Lyme.

Also patients will want to learn about the basic tests performed by each specialty to evaluate illness symptoms and underlying organic abnormalities.

Taking the U.S. ME Clinician's Coalition Basic Handout on the illness to an open-minded physician could be helpful:

<https://drive.google.com/file/d/1SG7hIJTCSDrDHqvioPMq-cX-rgRKXjfk/view>

For more information the doctor could consult the Diagnosis and Management portion of the site: <https://mecfscliniciancoalition.org/clinical-management/>

A more lengthy, but also readable and convincing Mayo Clinic validation and explanation of ME/CFS is: [https://www.mayoclinicproceedings.org/article/S0025-6196\(21\)00513-9/fulltext](https://www.mayoclinicproceedings.org/article/S0025-6196(21)00513-9/fulltext)

Your Physician may want to check out the U.S. Centers for Disease Control and Prevention ME/CFS website at <https://www.cdc.gov/me-cfs/index.html> The section includes information on diagnosis symptoms and treatment.

An excellent, short, general article for the family physician, written by Dr. Susan Levine, is “ME/CFS – What Every Family Physician Needs to Know” <https://solvecfs.org/wp-content/uploads/2018/02/Family-Physician-Winter-2018-MECFS.pdf>

For assistance in making the medical diagnosis of ME/CFS, the physician should be aware of both the Center for Disease Control’s Diagnostic Criteria: [IOM 2015 Diagnostic Criteria | Diagnosis | Healthcare Providers | Myalgic Encephalomyelitis/Chronic Fatigue Syndrome \(ME/CFS\) | CDC](#) You can print this out and take it to your doctor.

Also, a more detailed Diagnostic Criteria is the 2011 ME International Consensus Criteria at <https://dxrevisionwatch.files.wordpress.com/2011/10/international-me-consensus-criteria.pdf> You can print-out pgs. 329-331 for the specific Criteria to take to your physician.

Working with the Doctor or Other Provider

Once the individual has started with a knowledgeable physician or other provider, there are definite ways of preparing oneself for the appointments so as to get the most benefit from the time spent.

The patient needs to be focused and intentional in their communication with the doctor, so as not to waste time in tangential conversation. This is where making a list of items/issues to be discussed beforehand can be of help. Also understanding how a doctor works, how they conduct a session, and what they want to know will help the patient and doctor work together.

If there is a pressing issue that needs immediate attention, the patient should bring this up first so that the time will not end before the issue is dealt with.

Also, a good general rule is not to be afraid to ASK the important questions you have.

Patient and family Education about the Illnesses – A Necessity:

It is very important for a patient and their loved ones to gain knowledge about their illness – that ME/CFS and the other illnesses are physical, multi-system illnesses, including how these illnesses are diagnosed. They are not psychiatric illnesses that can be overcome by psychiatric/psychological treatments – or with a regimen of exercise that ignores the post-exertional crash. Or even the recommendation of “just getting on with your life.”

Sufficient knowledge of the illness(es) will allow the patient to make some evaluation of whether the doctor is properly diagnosing and treating. Patient illness education also allows the patient to participate constructively in their treatment.

Of course, the patient should not try to diagnose themselves -- they need a competent doctor’s medical knowledge. Nor should a patient attribute new symptoms to their ongoing illness – new symptoms should be taken seriously and might indicate a new and different illness which must be addressed.

Getting the right evaluation and diagnosis as soon as possible is critically necessary in combatting the illness.

Too many patients go from doctor to doctor for years before finding a doctor who provides the proper diagnosis and treatment. Being fortified with knowledge can help a patient in their search for a doctor and not waste precious time, energy, and even money in staying with doctors who do not help.

Resource List for Finding and Working with Your Provider:

“Healthcare Hurdles that Interfere with Productive and Satisfying Visits - Effective Communication Examples” – An excellent article on from the Bateman-Horne Center on the difficulties that ME/CFS and fibromyalgia patients may experience

with physicians – and some solutions to these difficulties.

https://batemanhornecenter.org/wp-content/uploads/filebase/education/top_resources/BHC-HowtoCommunicatewithYourProvider-7.2021.pdf

“Doc Talk - Effective Communication is at the top of everyone’s list when it comes to the patient doctor relationship”. Here are some strategies to enhance communication with your medical team and avoid leaving the doctor’s office feeling frustrated and depressed.

[https://web.archive.org/web/20050909032651/http://www.lifequestcoach.com:80/user/doctalk%20\(3\).pdf](https://web.archive.org/web/20050909032651/http://www.lifequestcoach.com:80/user/doctalk%20(3).pdf)

“Working with Your Health Care Provider – Tips on How to Get the Most out of a doctor’s Visit” Advice from ME/CFS Specialist Dr. Lucinda Bateman.

<https://www.massmecfs.org/working-with-your-me-cfs-doctor?start=2>

“Cheat Sheet for Doctor’s visits” – What to bring to the doctor’s visit:

<https://www.massmecfs.org/working-with-your-me-cfs-doctor?start=3>

U.S. Centers for Disease Control – Patient Tool Kit – includes: “Preparing to Discuss ME/CFS with a Health Care Provider; On the Day of the Office Visit After the Office Visit; After the Visit; Health Care Visit Checklist; Medication list;

<https://www.cdc.gov/me-cfs/resources/patient-toolkit.html>

“Talking With Your Doctor – Making the Most out of Your Appointment” – National Institutes of Health <https://newsinhealth.nih.gov/2015/06/talking-your-doctor>

An Excellent book is “How Doctors Think”, by Dr. Jerome Groopman of Boston and a professor at Harvard. He tells of his frustrations and difficulties when he, himself, became a patient.

National ME/CFS Providers’ Databases:

Solve ME/CFS list of ME/CFS Experts in the U.S. <https://solvecfs.org/wp-content/uploads/2021/11/Clinical-Research-and-Patient-Leaders.pdf>

ME Action Doctor List - <https://www.meaction.net/resources/find-your-doctor/>

Extensive list of physicians in England and the U.S. – some entries may be outdated. (Also contains extensive list of support groups in England and some Commonwealth nations).

American Association for ME/CFS – Doctor data base

<https://ammes.org/physician-and-clinic-database/>

Co-Cure Good Doctors List – An older list by State – some entries outdated

<http://co-cure.org/Good-Doc.htm>

List of various types of providers by state in U.S. – some entries outdated [United States Resources - cfsKnowledge Center \(ME/CFS\)](#)

National lists of ME/CFS and fibromyalgia support groups:

*ME Action Support Groups - nationally and by state:

<https://www.meaction.net/groups/>

American ME and CFS Society support group list <https://ammes.org/find-a-support-group/>

*ME/CFS Weekly Phone Support Group Every Saturday at 5 p.m. Pacific / 8 p.m.

Eastern U.S. Dial-In Number**: (609) 746-1155 List of International Dial-In

Numbers: <https://fccdl.in/i/mecfsphone>

Access Code: 915110#

*Facebook Parents with Children ME-CFS Support

Group <https://www.facebook.com/groups/295809457153118/>