



# Solve M.E.

## **Solve M.E. Patient and Caregiver Resource Guide:**

### **Finding a Doctor**

There are only a handful of specialists and clinical centers that specialize in ME/CFS around the country. Many of them do not take insurance and most have waiting lists that can be years long. Instead of seeking out a specific specialty, many people with ME/CFS focus on finding doctors who are 1) knowledgeable about ME/CFS or other complex chronic illnesses 2) willing to be partners in their medical care and 2) listen to their needs. The same is true for people with Long Covid.

#### **Making a “short list”**

While it is important to conduct research before choosing a physician for any healthcare situation, it is extremely important in researching physicians for treating a complicated illnesses like ME/CFS or Long Covid. Use online resources. There are multiple websites that rate doctors by patient reviews, healthcare review standards, credentials, specialty areas, etc.

Contacting local Hospitals and Medical Groups for referral lists of doctors in your area who are currently treating Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, or clinics that are accepting Long Covid patients, are great resources. And, don't forget to talk with family and friends about satisfaction with their current physicians. Word of mouth is one of the most reliable methods for finding a competent, caring doctor.

Equally useful, if not more so, is to search out opinions from persons with other chronic, debilitating illnesses. Here are a few patient-to-patient sources where you can begin your search:

For Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome:

- [#MEAction Global Directory](#)
- [Health Rising Forums](#)
- [CFS Treatment Guide](#)
- [American Myalgic Encephalomyelitis and Chronic Fatigue Syndrome Society's Physician And Clinic Database](#)
- [Phoenix Rising Forums](#)

For Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome:

- [Long COVID Support Groups](#)
- [List of State-Specific Facebook Groups](#)
- [U.S Post Covid Care Centers](#)
- [COVID Competent Health Care Providers](#)

We are pleased to provide this list of physicians and clinics as a resource. We have no professional medical relationship with these clinicians and have no connection to the websites on which their information is located. We cannot confirm the expertise or quality of care provided by these clinics – only that other patients have utilized them.

Hopefully, by this time, one, two or three names will begin to top multiple lists. You may begin to hear the same name repeated multiple times. The old adage, “cream rises to the top” remains true. If this is not happening for you yet, expand your database and begin again.

## **Interviewing your List**

Your initial appointment with the physician you eventually choose should be treated like a job interview. Remember, you are the one doing the hiring! If it doesn't feel right at the initial appointment, thank them politely and leave. Go to the second, and third person on your list if necessary. Keep going until it feels right.

You are paying this professional to deal with a very frustrating and confusing illness. Be upfront about your own expectations and concerns. ME/CFS and Long Covid can cause mental confusion on the best of days. Stress, most likely, will increase your mental confusion. Write your interview questions down. Keep your list of interview questions as short as possible, without compromising your ability to make an informed decision.

Allow the doctor time to give thoughtful answers. Sort your most important questions to the top of the list, with the realization your session could be cut short by the physician being called to an emergency. And remember, you have every right to expect any physician to give your concerns their genuine consideration. Be picky, you are making a serious decision.

Below is a list of interview questions that may be relevant in your quest to hire a qualified physician.

### **SAMPLE INTERVIEW QUESTIONS FOR HIRING A PHYSICIAN**

1. Approximately how many patients have you treated with (ME/CFS or Long Covid)?

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2. What do you know about (ME/CFS or Long Covid), and do you believe (ME/CFS or Long Covid) is a real and valid illness?

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3. Do you have a protocol for treating (ME/CFS or Long Covid)?

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4. Would you be willing to work in coordination with my other doctors? (If you have other doctors currently treating you.)

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5. [Add your questions here]

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If the doctor indicates they do not believe there is such an illness as Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome or Long Covid run, do not walk to the exit. Thank them for their time and leave. Go to the next name on your preferred physician list and repeat steps 1 through 5.

## **DOCTOR APPOINTMENT TIPS**

Whether you meet with a specialist, find a new primary care doctor, or choose to work with your current physician, the following tips may be of help:

1. Before your visit, think about your most problematic symptoms and write them down, along with any questions you might have for the doctor. It is far too easy to forget what you're doing once you've arrived at your appointment.

2. When describing your symptoms, give examples. Although it's common for people to tell the doctor that they're "tired all the time," few will explain that they need to lay down for thirty minutes after taking a shower or feel the need to sit down when standing in line. By being specific, you can help the physician narrow down the possible causes of your symptoms and identify potential strategies for minimizing their impact.
3. Take notes during the appointment, or if possible, have someone come with you to help. With cognitive impairment, it is common for patients to misunderstand or simply forget the recommendations that have been made.
4. Be an active participant in your medical care. Ask questions when you don't understand what has been said. Be sure you understand the purpose and side effects of any prescriptions or supplements that have been recommended.
5. ME/CFS and Long Covid are a complex and challenging diseases that are not well understood. If you are seeing someone who doesn't know much about the disease, consider printing and sharing the CDC's ["What Is ME/CFS?"](#) page or the ["Interim Guidance on Evaluating and Caring for Patients with Post-COVID Conditions"](#) for Long Covid. Although it may be frustrating to have to "educate" your doctor, do try to be respectful when sharing information. "I brought this just in case you haven't seen the latest information from the CDC about (ME/CFS or Long Covid)."