

*By Rebecca Bradley*

Chronic Fatigue Syndrome (CFS), or Chronic Fatigue and Immune Dysfunction Syndrome/Myalgic Encephalopathy (CFIDS/ME), sounds like nothing until you get it. Whether you are self-diagnosed and are still looking for medical validation or already have your "official" diagnosis, the initiation rites into the CFS/CFIDS/ME club are pretty much the same. There is an overwhelming fear of whom to believe and what to do. Questions roll around in your head, such as: What type of doctor do I need to see? Why do the symptoms change? Am I crazy? What do all the medical terms like EBV (Epstein-Barr virus), CFS (Chronic Fatigue Syndrome), FM (Fibromyalgia), NKCs (Natural Killer Cells), mitochondria and cognitive dysfunction mean?

In particular, when you speak with patients who have been around a few years, many of them seem more relaxed or knowledgeable about all the medical lingo and you may feel like a fish out of water. It is very typical for a new CFS/CFIDS/ME patient to feel overwhelmed and frightened, yet be determined to learn all they can to try and beat this illness. Patients tend to jump right into on-the-job training for their personal "medical degree," no college necessary. As patients, *we* are educating the *medical* establishment, one--on-one from the bottom up. That is why the old -timers appear to know so much. It isn't that they are smarter than you; they have just been around longer. You'll catch up.

Fear is one of the worst enemies. As the symptoms move around or change, it is not unusual for a patient to question his or her own sanity. How can so many things be wrong? Why does my mind not work when I want it to? Why do I still feel like a Mack truck is parked on top of my body after I've already slept 14 hours? If I rest, will this go away? Will I ever get better? Where did my life as I knew it go? How dare it go on vacation and not take me with it?!

### **Connecting**

To overcome fear, a good starting place is to join a support group, even if you can't always make the meetings. They may have a telephone buddy for you, or at the least, someone you can talk with occasionally. Connect to other patients and don't let ignorance or isolation keep you down. *Isolation is an enemy.*

### **As For Treatments**

There is a lot of misinformation out there. Some treatments help, some don't. That is a typical

problem for both doctor and patient. Each person may respond differently to drugs and dosages. Some patients prefer no treatment, while others seek aggressive intervention. Some want allopathic (standard medical treatment) while others turn to natural or homeopathic treatments. Many use a combination. You have to learn to listen to your body and take your cues from it. Over time, it will tell you what you need; when to rest, what works, what doesn't. Let your intuition be your guide and develop your "CFIDS radar." After all, no doctor knows your body as well as you do. Accept that, as patient—even if you were previously a medical professional —the assumption by many in the medical establishment is that a patient knows nothing. Change that stereotype. Don't blindly accept this type of attitude from a doctor.

Another idea is to get newsletters from several different patient organizations and groups. If you are able, read medical articles, speak with CFS/CFIDS/ME specialists, and if your area puts on a CFS/CFIDS/ME medical conference or has a speaker/lecturer, try to attend. Not only will you feel connected, you might learn something.

There is always plenty of floor space on which to lie down if your body gives out (most patients with CFIDS (PWCs) seem to carry pillows and drinks at all times). If you can't personally attend a lecture, try to get the information. Many support groups have information packets about this illness; many libraries lend out books and DVDs.

### **Training your Doctor**

Unfortunately, at this time, it is still rare that a patient can walk into any doctor's office and expect the doctor to know what to do. Treatment is still trial and error; but for those physicians in the know, there are many more tricks in the hat to try than a few years ago. Many inroads have been made in the medical community after years of advocacy and private research funding. The government is starting to let some money flow into researchers' pockets. It often takes many years for a new disease to get through the pipeline from acknowledgment, research, and a welter of medical publications to the level of clinical acceptance. Look at the time it took before the cause of most ulcers was pinpointed to be the *H. Pylori* bacterium. *H. Pylori* was discovered over 20 years ago, while ulcer patients were told their symptoms were caused by stress!

One big pitfall to look out for is the doctor who doesn't have a clue about ongoing CFS/CFIDS/ME research, and approaches CFS/CFIDS/ME like ulcers, i.e., "This is all in your mind; go see a psychiatrist." Many internists, and even specialists, feel comfortable making a psychiatric diagnosis with which they have little, if any, experience on the subject. How many psychiatrists would presume to diagnose a physical medical condition? (Kind of a one-way

street, it seems).

Also, don't buy into the hype that you are just doctor-searching to hear what you want. We all know there are a few—*very few*—people out there like that. But, if you are genuinely ill and get nowhere with the doctor you are seeing, go to the next. Whether you pay their bill directly or indirectly, doctors *are* our employees. Except, perhaps, in the case of HMOs— which may essentially own the doctors. It has now been proven by studies, and interviews with doctors who have left HMOs, that they were not allowed to give all options to their patients, or even worse, not able to order needed tests. Since CFS/CFIDS/ME diagnosis is still based only on a research definition from the government, with no single sure-fire test, everything related to CFS/CFIDS/ME can be labeled experimental and unnecessary. Hence you may need to fight the system and demand the care you need. Doctors who are clued in often can show definitive abnormalities on certain tests. There is something wrong in a CFS/CFIDS/ME body. It just doesn't say CFS/CFIDS/ME yet. Science only proves what already exists. It just takes too long sometimes.

At times, it may feel like you are being pulled through a tunnel with the hope of finding the light at the end—only to get there and find another tunnel. You ask yourself, "How many tunnels can I go through and still survive?" Know you are not alone, and eventually a light *will* glimmer.

The good news is that as you process information and begin to make connections the dots in this puzzle start forming a picture. You won't feel so fragmented. With education and knowledge comes power. You are in a better position to make educated and informed decisions about your own health care, working in a partnership with your doctor.

### **Taking Charge**

Another important point to make, and emphasize, is this: *Do not accept emotional abuse or, dismissive behavior from doctors*

Doctors have a responsibility to treat us with common decency and not threaten us or patronize us. They do not have to have all the answers or even understand this illness, but they need to treat us as humans. It is not acceptable for them to stress us out, either, but it happens all the time. Speak up when appropriate. Not every doctor is a good doctor (but assuming you find one, know when to ask for help).

*As a new patient, be patient.*

It is always frustrating because we want the answers not today, but yesterday. Slow down a little. If you can't, the illness will make you do it anyway. Ask to be treated symptomatically to reduce the pain, to help with the sleep disturbance, to handle dizziness and balance problems, to rein in the headaches, to control allergies, etc. Once you get a bit of relief, then you'll be in a

better position to start using your energy to read and learn.

Try not to let the initial stage of confusion and fear pull you down. Instead, as you add knowledge and connections with other patients, imagine yourself standing in the center of a circle. All the information you need is on the outside edges. As you pull the pieces from the edge toward you, you are in charge and getting continuously more knowledgeable.

Being forced to adopt major life-altering behavior as a result of a chronic illness creates enough trauma. Recognize this and it will make it easier. Lying in bed thinking of all the things you could do if you could just get up will only stress you out more. It may take a while to learn new behaviors and attitudes. Many patients come from a background of being independent "over-achievers" used to getting things done. Adapting is difficult—but necessary.

To better days!