

## **Meeting the Independent Physician for Disability Evaluation**

*by Jennifer Camphill*

Many people with Environmental Illness end up having to apply for disability, either through Social Security or some form of private or state plan through a workplace. This is a long process that takes months and even years. Mine took 18 months, which seems typical, though I know several people who had to fight for years. Start early, you can always cancel if you don't need it, but don't start while still working.

One of the most important steps in the process is the evaluation by a physician, who is hired by the agency considering the case. Some of these physicians are exclusively doing this type of evaluation, while others see their own patients as well. These physicians can be hired directly by Social Security or through private agencies which provide experts for court cases, insurance claims, etc.

It is important to realize that this step in the disability process is very unlike consulting a physician for medical care, and is adversarial in nature. The chosen physician has never met the applicant before, and is usually not working directly for the agency considering the case. They are therefore considered objective, though they are not fully so, as they are paid by one side of the dispute.

The physician is expected to find reasons to deny the claim. Some see it as their responsibility to try to expose malingering, even by trying to trap the applicant with their questions.

The object of this meeting is, for the applicant, to convince this physician that it is not possible to work. The opinion of this physician has more weight with the agency than the support of several physicians who actually know the patient, and the agency is very likely to deny the claim if "their" physician does not support it. Even if their own physician supports the case, the agency may still deny it.<sup>(1)</sup>

It is "safer" for a physician to say a patient's health is pretty much fine, with no significant objective signs of disability, than to stick her neck out to support a controversial diagnosis and recommend disability. One physician I went to was clearly weighing this when he asked at what stage I was in the process — whether this was the first round or the appeal case. Since denial of the initial application is pretty much standard, his support there would not make much difference anyway.

As there are no objective ways to prove the existence of MCS or Electro Sensitivity, most physicians still do not believe they exist, and that makes it extra hard for them to be supportive.

Most of the doctors are of course very professional, though of the four doctors I was sent to, one stared at me stone-faced the entire time, while another actually sneered at me when he saw that my primary physician is a well-known physician in environmental medicine.

Each physician works differently, so one never knows what to expect. One I was sent to does treat some people with MCS. The agency finally sent me to him when I complained in my appeal case that I had yet to be seen by a physician who was competent in the field of Environmental Illness. I expected to be well received, but he basically lectured me for 90 minutes about largely irrelevant topics, interspersed with shallow questions to which he would only allow me very brief replies. He even asked a lewd question regarding my sex life during college! To top it off, he wanted me to come back as his patient. Abuse of power comes in many packages.

The other doctors the agency sent me to were nicer, though they too control the conversation and leave little room for bringing up things they would not think about — which is basically most of the types of problems and issues that prevents an EI from working.

The specialty of the physician is very important and is decided by the agency. An allergist is a common choice, and is unlikely to be supportive when meeting a patient who talks about Environmental Illness, the very existence of which seems anathema to most allergists, though certainly not all.

Another common choice is a psychiatrist, and many of us end up with some sort of psychiatric label. Since MCS and EHS are unprovable and lack acceptance, it may not be on the agency's "list of approved disabling disorders". If no other label is usable, a psychiatric diagnosis may be the only possible way to get through the system, however uncomfortable that may feel.

The good thing about psychiatric diagnoses are that they are not objective. There are no blood tests that can show anything as proof, so the psychiatrist often has greater flexibility than other types of physicians.

All physicians are restricted to practice their own field. They can be censored, or even prosecuted, if they go too much outside their own field of expertise. This does not restrict an allergist from suggesting in her report that the patient should be sent to see a

psychiatrist, or that her impression is that the problem is psychosomatic; but only a psychiatrist can actually make such a diagnosis. Likewise, a psychiatrist cannot say that a patient is disabled with MCS or any other condition outside their field.

When mounting an appeal or court case, the choice of specialty of the evaluating physician could perhaps be used as an argument.

Doctors are trained to exude confidence. It's a necessary part of a professional job where people pay good money for the professional's opinions and expertise. A professional who is not sure of herself will soon lose business. Patients have to believe in the pill they are given, or they may not take it; and even if they do take it, it may not be as effective as when they had faith in it. However, this necessary confidence can become sheer arrogance in some individuals. The medical field has a lot of internal politics: doctors in one field consider themselves a little "better" than those practicing in other fields, for instance(2). We as patients can be caught in this when we show up and by our very presence question that the earth is flat and that it may not be the center of the universe after all. That is very threatening, and the response can be very human. Medicine has put its collective head in the sand over many "new" things before, when it threatened the comfortable status quo, whether it was the existence of germs, Lyme disease, Multiple Sclerosis or AIDS(3--7).

Then what sort of approach to take when actually sitting in the hot seat, probably not feeling too well in a regular office, and faced with a person who has a great deal of power to influence your near future? I think it's the same as for a job interview or a first date: be yourself.

A physician will especially be looking for any sort of malingering, and if any is found, the case is likely to be closed immediately. It is tempting to "pad" the responses a bit, as surely the physician expects some of that and thus subtracts from the answers, but it is hard to do that consistently and any inconsistencies could cause problems.

If the physician uses any sort of test, like memory tests, it is tempting to pretend things are worse than they are. It is very hard to do that fully consistently on such tests, and even people with serious brain damage can get quite a number of these types of tests correct, and the physician will be well aware of that(8). Malingering is a slippery road, that should be quite unnecessary.

It is important to be honest emotionally, too. If anger or tears come easily, let it show. Emotional instability may help the case, if some sort of psychological disorder is being considered.

I think it is very important to show an interest and willingness to come back to work. I do that by talking positively about my former job and career (which I very much liked), and the frustration from having been sidelined in life. People who wish to achieve things are less likely to be malingerers.

I do wear a mask in the doctor's office, even though the effects of a normal office might provide more evidence to support the case. I have found that physicians do not notice the effect on me, which is that my thoughts become cloudy, I clam up and just give short replies without elaborating with important details. For people with more obvious responses, it may be a good idea to go unmasked, but this should be considered very carefully in advance. I did sense that two of the physicians were a bit uncomfortable with my mask, though neither said anything directly.

Even with the psychiatrists, who are trained listeners, I left a lot unsaid. It is difficult to think of everything in such a situation, especially if the air quality is not pristine. As an aid, I bring along a list of "talking points" — a one-page list of issues to cover during the conversation, including:

- symptoms, causes and duration
- things I used to do
- places and situations that are a particular challenge

As I often can't even remember all the symptoms I may get from various things, I make a short list for the different items, so it can serve as a handy note.

The person on the other side of this conversation is very unlikely to understand what impact our sensitivities have on our ability to work — just see how difficult it is for people who know us well — so it is imperative to paint a picture of the difficulties, to make it at least a little understandable. Even if the physician thinks it is all psychosomatic, she may at least realize that life is very difficult.

Gaining this basic understanding is very hard to achieve, even in the best of circumstances. To further educate the physician in a more comprehensive manner, I started giving the physician the most important information in writing, so she would have it even if I wasn't allowed to say a word during the meeting. Each time I added more details, so it became several pages, each covering a specific subject, such as a list of symptoms or "daily challenges" with a paragraph about each issue that affects my daily routine. Another sheet details my housing situation and yet another tells the story of the last six months of my work life, as well as some information about my professional career.

I included a personal letter stating that I know there would not be time to cover all these issues during our meeting, and pointing out that even though this diagnosis is controversial, so were AIDS, MS, Lyme Disease and Asbestosis until recently. Nice and non-confrontational. I once even included the housing-ads page of *Our Toxic Times*, to make the point that I am not alone.

I also make sure to include a full set of the lab work done by various doctors. Mistakes do happen at the agency, and I found out that they did not supply the psychiatrists with the non-psych lab reports.

I give the physician all the materials at the end of the session. One big envelope for the lab reports, one for letters from doctors, another for my letters, etc. It is important to make it easy to look at.

A friend pointed out that being "too clever" could have backfired, with the logic that if I could produce this material, then I must be quite functional. I counteracted that by dating each page, so it was obvious they were written over a year.

A comment in one of the physician's reports was that he considered the volume of the material to indicate how much I had "bought in" to this illness.

It is the policy of my agency that they will release the reports they get back from their physicians, but only to my own physician or attorney. Getting this feedback can be very informative and helpful when appealing a denial. It can also be rather amazing and disturbing to read these people's impressions. I used this feedback to improve the set of materials I supplied to the next physician, such as explaining what a "booth test" is, though I doubt a physician will have much faith in what a lay person says.

The reports told me that the neuropsychiatric test I had done in Dallas was very valuable, as nobody really called it "subjective" or "unscientific" (or whatever wording they use to dismiss most things with). This test measures how well the memory and various cognitive skills are working.

It was interesting to see how the physicians interpreted the lab work, which varied widely and included deceptions, omissions, cluelessness and even a few outright lies. They generally only commented on reports from their own field.

The letters from supporting physicians that I provided were dutifully noted by all physicians, so they do seem helpful as well. It may be well worth it to invest in going a few times to a physician and do some lab work there, before asking for a letter. Some are not willing to provide one, since it takes a lot of time and is poorly paid. They may also be sticking their neck out a bit, so many are reluctant to do it even for long-term patients.

In addition to the lab reports, the letters from supporting physicians and my own statements, I also give the physicians educational materials. The booklet "Multiple Chemical Sensitivity"<sup>(9)</sup> is an excellent concise description, by a physician, so it carries some weight. I also include a few selected medical articles, most of which are obtainable through CIIN. I doubt that they will take the time to read all this, but some of it may catch their interest.

The physician is very unlikely to agree to any special accommodations, such as meeting outside the building or not wearing smelly clothes. I even tried with a letter from my doctor, which was flatly denied, using the reasoning that if I could go in the first doctor's office, I could also go in the next one's.

The independent evaluation is a difficult step in the disability process. It is not intended to be easy, perhaps not even fair, and the best preparations do not assure success. To me, it seems more like a lottery than the scientific evaluation it claims to be, but a little preparation can improve the odds. I found it worth the effort.

And when we finally make it through the whole process, we get to meet these physicians again at the periodic reevaluations. At the start, they'll happen every couple of years (one to three years is typical); later, less frequently. These reevaluations are easier, since the physician now just needs to confirm what other doctors have said.

*The author has been evaluated and reevaluated by seven different physicians.*

- (1) Alexander Vlantis vs. Kenneth Apfel, Commissioner of Social Security, United States District Court for the District of Connecticut, Sept. 22, 2000. (CIIN: 0147-SSCT-00-027)
- (2) Perri Klass, M.D., *A Not Entirely Benign Procedure*, Penguin Books, 1987
- (3) Paul Trachtman: Hero for Our Time, *Smithsonian Magazine*, Jan. 2002
- (4) Ann McCampbell, M.D., *Multiple Chemical Sensitivities Under Siege*, *Townsend Letter for Doctors and Patients*, Jan. 2001
- (5) Robert O. Becker and Cary Selden, *The Body Electric*, Quill, 1985
- (6) Randy Shiltz, *And the Band Played On – Politics, People and the AIDS Epidemic*, St. Martin's Press, 1987
- (7) James P. Lawrence, M.D., FCCP, *Asthma . . . What Everyone Needs to Know*, *Our Town Magazine*, Feb. 2003

- (8) Brett Trowbridge, PhD., JD, Malingering Exposed, The Trowbridge Foundation
- (9) Ann McCampbell, M.D., Multiple Chemical Sensitivity, 1998. Send \$4 per booklet (discount for 10 or more) to Ann McCampbell, M.D., 11 Esquile Road, Santa Fe, NM 87508. Make check payable to "Ann McCampbell, M.D."