

## **How to apply for disability benefits when you have a chronic controversial illness (MCS, EHS/EMR-S, CFS/ME, fibromyalgia, etc)**



**Your chronic illness is controversial in the eyes of people who don't have it themselves, and it is getting so bad you can no longer work. You have to apply for disability benefits. If this is you, read on.**

*Keywords: disability benefits, incapacity benefits, environmental illness, multiple chemical sensitivity, MCS, electromagnetic hypersensitivity, EMR syndrome, environmental sensitivity, CFS, ME, fibromyalgia, SSDI, SSI, Social Security,*

We describe the application process in general terms, that should be helpful regardless which country you are in, and whether you have government or private insurance. We do mention some particulars of the United States Social Security Administration (SSA), which offers two disability plans, called SSI and SSDI.

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This document is based on the author's own experience applying for two different disability plans (and eventually winning both), several "war stories" from other people, and other sources, including an excellent book listed at the end.

Our focus and experience is with multiple chemical sensitivity (MCS) and electromagnetic hypersensitivity (EHS), but the material here should also apply to people with other controversial disabilities, such as chronic fatigue syndrome/myalgic encephalitis (CFS/ME), fibromyalgia, photosensitivity, hyperacusis and others.

This is not legal advice. For the most effective help, you'll need a lawyer specializing in disability law, who is experienced handling your particular disability.

### **You must stop working before applying**

Most (all?) agencies will automatically reject your application if you are still working. Their logic is that if you are working, you are able to work. They do not care how hard it is, or how little you actually accomplish at work. There is no grey zone. (The SSA has such a rule.)

If you can, go on sick leave before you apply. Since the application process takes several (or many) months, you will likely run out of sick leave and perhaps have no income. In most countries, the social services will help you during this period if you run out of savings. In America, many have had to live off their extended families through the application period.

### **Before you quit your job**

If you live in the United States, most large employers have insurance plans that will pay their employees if they become disabled. This is to supplement the meager SSA payments, and also cover those people who have not worked long enough to be covered by the SSA. If you quit your job, you'll lose this insurance. (some do cover for a limited period after quitting, some do not).

Call your personnel department or look at their website to see if there is such an insurance policy. If it is a large firm, they may even have someone on staff who can help you apply. Such a person can be a great help navigating the process.

Some people quit their well-paying jobs, hoping that a less-taxing job, or no job at all, would help them recover. When that didn't help, they discovered that they no longer qualified for their old company's insurance plan. Some were out of work so long they didn't even qualify for the government insurance (SSA).

The SSA will still accept you some time after you have stopped working. Their rules for how long are complicated, but in general don't wait longer than one year.

You can always withdraw your application if you recover, but you can't get "in" if you are too late.

If you try to start in a new job, be aware that the company's disability insurance may not accept you before having worked there for several years (5 or 7 are common in America).

### **You need a "good" doctor**

It will help your case if you have gone to the same doctor for some time. The doctor must be one "acceptable" to the agency, they will not accept a chiropractor, herbalist, homeopath or similar alternative practitioner.

In America, you'll need an MD, DO or Ph.D. psychologist. A few agencies may also accept an ND or NMD (the SSA does not).

Your doctor is crucial for filling out paperwork when you apply. Some doctors don't like to do that, since it isn't paid well. A doctor you have a long-term relationship with should be more willing.

Choose your doctor wisely. If your doctor prescribes drugs that you cannot use, the doctor may report you as not following medical advice, which the agency will heavily frown upon. Make sure the doctor understands all the side effects you get from trying those drugs.

It helps your case if the doctor can report to the agency that you have tried all sorts of things. They like to see people trying to stay in the workforce.

Finding a doctor who is willing to work with someone who has environmental illness can be difficult. You may have to travel great distances to meet with one. Ask around the EI community for referrals.

### **Illegal or addictive substances**

If you self-medicate with any illegal or addictive substances, including alcohol or marijuana, you should stop. The agency is very likely to ask specifically about these things. They may reject your case just for that reason.

Marijuana is currently outlawed by the US Federal government. That is what counts, not whether your own state allows it.

### **If you are covered by multiple agencies**

If you are covered by more than one agency, say the SSA and your employer's insurance plan, you are in luck. It won't be a bonanza, they usually have clauses that reduce their payments if you are covered by multiple agencies, but it is still better than one.

Do apply to all the agencies, even the one that'll pay nothing if the other one comes through. You may find that one agency comes through much faster and can carry you over while you go through the appeals for the other. Appealing can take a year or more.

You may find that the agency that approves you first then becomes your ally in battling with the other agency (if you win, they save a lot of money). They may furnish you free legal help.

### **The criteria they use**

Each agency has its own rules for determining whether it will pay you disability benefits or not.

The most important rule is whether you must be too disabled to do *any* job, or just your last job. This makes a tremendous difference. It is easier to prove you cannot do your last job than proving you cannot do any job.

The SSA requires you to prove you cannot do any job, even a job you are way overqualified to do, and which will mean a steep cut in pay.

Some agencies will accept a partial disability, meaning they will pay you less and expect you to have a part-time job of some kind. In America, most are all-or-noting (including SSA).

If you can work with some reasonable accommodations, they may not consider you disabled. Whether your present boss is willing to accommodate you or not is often irrelevant to them. You can just get another job somewhere else, they reason (never mind companies are notorious for not hiring disabled people, and as a new employee asking for an accommodation is extra difficult).

Your age is important. If you are young, it will be harder to get approved since they don't want to pay you for many decades. A younger person is also more likely to get well, and can do physical labor an older person cannot do.

The SSA is more lenient on older applicants, using steps for ages 50, 55 and 60. Your agency may have similar rules.

The agency will have an internal list of diagnoses that qualify for disability. If you are not on that list (which is likely the case) the agency will do an individual assessment, and likely reject your application on the first try. If you provide good paperwork, they may accept you on the first try, but don't count on it.

The people who make the decision will never see you, all they have to go on is the paperwork they get from you, your doctor, and the consultants they use (such as a physician they hire to examine you).

Since MCS, EHS and other chronic illnesses are so poorly understood (due to lack of funding for science), and there are few usable lab tests, they will have to make a more holistic decision instead of checking boxes on a sheet. You need to give them enough material to do so. This is really important.

### **Putting together the application**

The agency will give you a lengthy form to fill out. You will need to do more than just that, since you have such a controversial disability. You will need a letter and other documentation from your doctor. You should also consider getting some lab reports from specialists (see below).

The letter from your doctor is very important. Your doctor may not remember all your symptoms and limitations, so make sure to discuss them when you meet and ask for the letter. It can be helpful if you give your doctor a list of these things on a piece of paper.

You should also submit a detailed statement describing how your disability limits your daily life outside work. Be specific. Include what your symptoms are. If you have lost friendships, or you can only meet friends outdoors, state that. Can you still go to restaurants, movie theaters, stores or use public transportation? Does the disability make you more isolated and lonely?

If you don't use cell phones or computers, or have to drastically limit how much you use them, do tell.

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Have you modified your home in any way? (shielded bedroom, removed carpet, etc). What about your lifestyle, do you only use non-toxic detergents, cleaners, and personal care products?

Do you rely on other people to do what you'd do yourself, if you didn't have this disability? Do you pay them for the work?

Write about the difficulties you faced at work, and how you tried to overcome them (sitting next to an open window, go outside to recover, work from home, etc). If you went on sick leave to try to recover, describe how that went. Did it help?

It would be more believable if your boss also wrote such a letter. You could write a draft letter, which your boss could then edit. That would produce a better result and be much less of a burden on your boss, i.e. the chance it happens is much greater.

If you have involved a landlord in any modifications to your home, consider asking the landlord for a letter describing that, and any other observations the landlord could make to support your case. Offer to provide a draft for the landlord to edit.

Letters from third parties who have nothing to gain are more believable than what you write yourself. Besides a boss and landlord, you may try to get such letters from other people who know you well, such as friends, neighbors, coworkers, clergy, etc. Be aware that writing letters are intimidating to a lot of people, especially if they are not sure what to say. Again, offer them a draft you make yourself.

Spend a lot of time working on these letters. Work on them over several days as you think of more things to add, re-read what you wrote, revise. Well-crafted letters will be taken more seriously. They can make the difference between failure and success.

If you are not used to write well-crafted letters and reports, get the help of someone who is.

These letters should be added to your application package.

If you have any visible signs from exposures, consider taking photos of that as documentation. One woman got nasty rashes on her face when using a computer, which showed up well on a close-up picture.

## **Include other problems**

If you have other medical problems, consider mentioning them. They may add up to get you past the finish line.

If you suffer from depressions, anxieties, back problems, arthritis, pain in your wrist when using a computer, or other things, they may help your case. They can give the examiners something they can work with when trying to fit you into one of their slots.

Just be aware that whichever slot they fit you into is what they'll focus on when later re-evaluating your case, and any improvements they look for. And you'll be expected to actively work on treating that particular disability.

## **Lab reports**

The agency is very interested in any objective signs that you are disabled. That means lab reports. Numbers that are only marginally outside the norm will not impress them. They need real abnormal data.

The following may only apply to people with MCS or EHS. The problem for these folks is that very often all the regular lab tests show normal results.

There are a few tests that often do show abnormalities and can be helpful.

A neuropsychological evaluation is a battery of tests probing how the brain handles various tasks. People with EI tend to fail some of these, especially involving short term memory. This evaluation is done by specialized psychologists, much preferably someone who does it on people with your disability.

There are hundreds of tests to choose from. It is important to choose well. A common one is the QEEG.

Balance testing (posturography) usually also shows abnormalities. Try to walk a straight line, one foot in front of the other, while blindfolded. There are more sophisticated tests that can document this.

Some brain scans (imaging) can also show abnormalities, especially SPECT and PET. Some very promising tests are being developed by Belpomme and Irigaray in Paris, France (consider going there).

All of the above tests are costly and require special equipment and expertise. They may not be available in your state or region. You may have to travel far to find a specialist who can do them.

Of the three tests, the one that has been the most helpful is the neuropsychological evaluation. That seems to be the one that is the hardest to “explain away” by the agencies.

When you do such tests, do not try to make things worse than they are. Even people with extensive brain damage can do some of them, and the tests are designed to detect fakery. If you need to apply for disability, you will likely be surprised how many of these tests you fail to do well, even when you do your best.

Make sure that you, yourself, have copies of all reports. The agency may lose what you send (it has happened).

### **Examination by their doctor**

Expect to be sent to be examined by a doctor hired by the agency. They will pay for this.

The exam should take about an hour. The doctor will ask you all sorts of questions. Some may seem strange, but serve to check how your mind works.

Be yourself. Don't try to act in a certain way. Be cooperative. Always tell the truth. You have come this far because you are sick, you don't need to embellish anything. These doctors are trained to look for lies.

Don't try to impress the doctor with your knowledge of medical terms, or to educate the doctor about environmental illness in general. That will likely just cause annoyance, at least with American doctors. (A single booklet may do.)

In America, many of these doctors are quite arrogant and will not allow you to speak at length. Instead, they will ask you questions, even if they don't know enough to ask the important questions. You just have to play along, no matter how unfair it is, and try to interject what you can.

They may have read the letters you submitted to the agency, but don't assume so. The agency may have only sent the lab reports. Consider bringing copies of what you wrote.

If you are so lucky your agency will consider you disabled if you can't do your normal job, make sure the doctor know this. In America, where the SSA

dominates, many doctors will just assume they are to follow the SSA rule of you being disabled if you can't do *any* job at all.

These doctors are specially trained to evaluate disabilities. They are also believed to be more “independent” than your own doctor, so the agency will trust their judgment more than your doctor's. (Until 2017, the SSA was supposed to give your doctor more weight, but not any more).

You may be sent to a second doctor, if the first doctor recommends it. The first doctor may suggest you have a psychiatric illness, so you'll be evaluated by a psychiatrist too.

### **Be pragmatic**

At some point, you'll likely have to make a choice. Chronic illnesses are poorly understood, and yours may not even be on the agency's list of conditions that are considered disabling (especially MCS and EHS).

You may get in the situation that the agency is looking into giving you disability benefits based on some sort of psychiatric diagnosis. They may send you to be evaluated by a psychiatrist.

This is unfair, stupid, and undignified. But the choice you'll have to make here is to swallow your pride, or lose.

There are people with MCS who refused the offer and kept fighting for a proper diagnosis, and lost everything. Is your pride worth that? The vast majority of EIs in that situation accept what is possible, and get on with their lives.

### **Job trials**

In some European countries, they may send you on a “job trial.” You will be sent to an employer who is used to do these trials and is paid by the agency to do them. The employer will try to accommodate your disability to see if somehow they can make it work. The idea is to avoid paying you disability benefits, or only pay you partial benefits if you can do a part-time job.

These job trials last weeks and can be very unpleasant for people with environmental illnesses.

### **Observing you**

If you go to an office to apply or otherwise meet someone, be aware that ALL staff is observing you. This can help your case, or not, depending on how they

interpret what they see. That is especially if you seem much more functional at the front desk than when you meet with someone. Toughing it out and acting healthy (as we often have to do) is not to your benefit. But don't fake it either.

One person with MCS had a friendly chat with an examining doctor's front desk person. Details of that conversation were included in the doctor's report (in a helpful way).

In any SSA office, it is routine for all staff to report their observations.

### **Beware of possible entrapment**

It has happened that an agency hired a private detective to follow an applicant around. One applicant was denied based on a video showing her in a hair salon, some stores, a clinic and a café. Never mind she waited outside for her turn and the café was organic and non-toxic inside; those important details were not shown in the video. We have an article about this issue, see the link at the bottom.

### **If you are denied**

The majority of people with environmental illnesses are denied on the first try. They don't fit nicely into any of the slots the agency bureaucrats like to use. Don't get discouraged, it is just another hurdle.

A 1996 study by Pam Gibson found that 77% (82 out of 111) of people with MCS eventually succeeded.

Be aware that there will be short deadlines for you to request each level of appeal. Meanwhile, the agency usually does not face any deadlines.

If you fail to file before a deadline, you can instead file a new case and start over. *Make sure* to include some new evidence or the agency may reject it right away.

### **Appealing your case**

The appeals process is different from agency to agency. The SSA has a five-level appeals process, private insurers tend to have fewer levels.

The first level of appeal is likely to be a "reconsideration." Here the same paperwork is looked at again, but by someone who has not been involved in your case before. You do not need to do anything other than make the request.

It is rare people win on this appeal. You should use the time to work on the next appeal, as that can take a lot of time and you will face deadlines.

At a minimum, get a copy of the report they got from the physician they hired to examine you. Some agencies will send it to you when asked, some will only send it to your lawyer or physician. Getting the report takes time. Start now!

## **Full appeal**

The terminology varies with the agency, but at some level of appeal, they will do a major review of the case. It will help your case a lot if you can provide some sort of new evidence. Especially helpful are any lab tests showing abnormalities, such as those listed earlier. You can also ask another doctor to write a letter supporting your case.

Also, put more effort into getting other people to write supporting letters. You can also write more yourself.

It is especially important that your doctor writes a rebuttal of the agency doctor's report, and any other material you can get from the agency.

You may also write a letter complaining about the doctor they sent you to, or get your own doctor to mention it. The things to complain about is if the doctor only saw you for ten minutes, or kept cutting you off so you were never able to say what you needed to say.

You can also complain about the doctor's competence to evaluate your case, if the doctor is an allergist or some other specialty that does not actually treat people with environmental illnesses (discuss this with your doctor).

This all takes a lot of time. Doctors are notoriously slow to write letters. The agency will give you a deadline to file the appeal, and it may not be enough if you don't move fast (some agencies allow for extensions.)

This stage is the one you are the most likely to win. If you don't, the next stages become more difficult and expensive, and your chances are less promising. So, you need to get really, really serious about doing everything you can to help your case.

Some agencies do this appeal as a redo of the application. They will send you to a new doctor for evaluation, perhaps even two.

The SSA will send you to an Administrative Law Judge. This is much less formal than a criminal court. You can present witnesses for your case, while the SSA will

provide “experts” stating you are not disabled. The judge has the power to overrule the SSA’s denial.

We have provided a separate article with details about how to handle the appeal to the SSA judge. It is available through the link at the bottom of this document.

### **Claiming you can do some work**

The agency may say you are not disabled enough, as they think your disability can be accommodated in some way, or you can switch to another job.

They may say you can work from home with a computer, and participate in meetings using videoconferencing (Zoom, Teams, etc).

Most employers who allow staff to telecommute still require them to spend a part of the week in the office. Will that work for you? Will your current employer make an exception for you? Do you think a new employer would?

The agency may suggest some other type of job for you, where they think you are not exposed to your triggers. People with MCS have been told by the SSA that they can work as a parking lot attendant, or in a so-called “clean room” where computer chips are manufactured. (Despite both jobs actually expose people to toxic fumes. The agencies can be quite clueless.)

Take these assertions very seriously. Research what such setups actually entail in real life for someone like you. If you can’t refute what they say, you’ll lose your case.

### **Further appeals**

There should be further appeal stages. You will need the help of a lawyer. The final level is a lawsuit against the agency.

### **Lawsuits**

Suing through the regular court system to get your disability benefits is perilous and difficult. The other side may use dirty tricks and personal attacks to try to discredit you, such as hiring a detective to spy on you (see link below for more on spying).

The website [defenseinformationcenter.com](http://defenseinformationcenter.com) caters to defense lawyers in the United States. It suggests strategies for fighting *against* disability claims. It may be helpful to look up the diagnosis and types of lab reports you intend to present in court, so you know what may be coming.

## **Treated like a juvenile**

Some agencies treat their applicants as if they are a mentally retarded ten-year-old. They don't allow you to make your own appointment and talk to you in letters and over the phone in stern tones that leave no uncertainty on what they expect and that any mishaps by them is actually your fault.

This can be insulting and disturbing. You did send in that form on time, which they apparently lost, but blame on you.

The excuse for such behavior may be that they deal with all sorts of disabled people, including some with serious mental dysfunction. They just treat everyone the same way, according to the lowest level of functioning.

Or if they've given you some sort of psychiatric diagnosis, that may be why they treat you that way.

In any case, it is best not to challenge them. You don't want to attract their attention, since they may then do a re-evaluation sooner. Bureaucrats can be vindictive when challenged.

## **The consequences of a psychiatric diagnosis**

Many people with chronic illness end up with a psychiatric diagnosis. The agency simply cannot fit you into any other slot in their system. Psychiatric diagnoses are flexible and less based on science (much less than the psychiatrists claim). So they fit you into one of those. They have a great many to choose from.

Some of the insurance agencies in America have clauses that they will only pay disability to someone with a psychiatric illness for a few years (2 or 4 years are common). Also, psychiatric treatments may not be covered much by their health plan.

The SSA does not currently have such discriminatory rules.

They will likely require you to be treated by a psychiatrist or psychologist. Psychiatrists may impose dangerous drugs on you. A psychologist never uses drugs.

At least privacy rules will keep the number of people who know you have a psychiatric diagnosis to a minimum. There is a serious stigma to having a

psychiatric diagnosis and people aware of it are less likely to accommodate your physical needs, including doctors and other medical staff.

### **More information**

The book *Nolo's guide to Social Security Disability*, by David Morton, is highly recommended. Read it, even if you are not applying to the SSA, much of it applies to all other agencies too.

We have additional articles about applying for disability benefits when you have some sort of environmental illness. They are at [www.eiwellspring.org/disability.html](http://www.eiwellspring.org/disability.html).