

## How to keep your disability benefit payments when you have environmental illness (MCS or EHS)



**You've been awarded disability payments and benefits. Now you should make sure you can keep them as long as you need them.**

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The following discusses what you can expect, regardless of which agency that provides your disability payments. Be aware that there can be attempts at entrapment.

Many countries have one single government agency that makes disability payments. In the United States there are many such agencies, both Federal, State

and private insurance. The big agency in the United States is the Social Security Administration (SSA). You may be so lucky to be covered by more than one.

## **Reviews**

The agency will review your case from time to time to see if you are still disabled. They may also verify that you see a doctor on a regular basis to try to get better. And they simply want to know whether you are still alive or not.

Each agency has its own rules. Some are open about their rules, some seem to consider their rules a deep secret.

There are different levels of reviews. For a simple review they just send you a short questionnaire, typically asking if you still consider yourself as disabled, and whether you have done any paid work. They may also ask when you last visited your doctor.

For a medium level review, they want to hear from your doctor. They either send you a form to bring to your doctor, or they send it directly. The form will ask about your current diagnosis, what treatment you are currently doing, and similar questions. They may also ask how often the doctor sees you.

For a full review you are probably sent to be evaluated by a doctor chosen by the agency, and paid for by them. The agency may use a referral service to choose the doctor and set up the appointment. It will always be a doctor who has never seen you before.

## **Triggering a full review**

The form you return back to the agency can trigger a full review. If you state you did paid work, or the medical information shows improvement over the previous review, that is likely to trigger it.

The form is probably scanned and “read” by a computer. If the computer has trouble, it may send you a note that it can’t understand (or even that they never received the form). If a human will have to look at the form, that greatly increases the risk of a full review.

In general:

- Never attach anything
- Never write outside any box
- Write legibly
- Do not include note of new name or address, unless there is a box for it.

## **How often they review your case**

Each agency has their own rules. They decide how often to review your case, and how detailed a review to do, based on whether they think you will get better or not.

Some agencies will do a full review of an EI case every year for several years, and then consider you permanently disabled (doing only simple reviews after that). Others may leave you alone for several years, and then do a medium or full review.

Some (such as SSA) will tell you when to expect your next review. Others will not tell you anything, until you receive a summons in the mail to be at a certain doctor's office in ten days or bad things will happen to you.

## **Your age is important**

If you are a younger person, the disability agency will be more eager to declare you well and able to work than if you are older.

In general, a younger person is more likely to get well again than an older person. And they would rather not pay a person for several decades.

They also know that a person who has been out of the workforce for several years tends to lose basic job skills, such as showing up on time and accepting the boss' orders. Such people have few job prospects.

Your disability agency may not tell you what their age rules are, but the American SSA does. They go easier on people once they are past 50, 55 and 60 years. Your agency may have similar rules.

## **See a doctor regularly**

It is important that you see a doctor regularly. That probably means at least four times a year. Some can be phone appointments, but you may need an in-person visit once a year. The rules are changing with the acceptance of telehealth appointments using a computer.

If you don't meet your doctor regularly, the agency may determine that you are not trying to get better and cut you off.

Some agencies may directly specify you need to see the doctor a minimum number of times a year (four seems common).

## **Follow doctors' orders**

The agency may ask what treatment you are currently trying, when they send you a review form. A doctor examining you on behalf of the agency will probably ask. It does not look good if you answer "none," unless you've been disabled for many years and can say you've tried all sorts of things that didn't work, or had terrible side effects.

If they ask your doctor what treatments you are doing, and the answer is you refuse treatment, that can result in termination of your benefits.

The problem is that doctors and agencies tend to think treatment only means drugs. They don't think eating organic foods and breathing clean air is a treatment. And they don't know people with environmental illness very often are sickened by pharmaceutical drugs, both the drug itself and all the other stuff in the pill.

You may have to try some drugs. The safer way to do that is testing for safety before you test whether it actually helps. You do that by first taking a much smaller dose than prescribed to see what happens. Then gradually increase the dose to the prescribed strength.

Write down what symptoms you get. If your living situation gives you symptoms too, so you are not sure which is which, you could look up the common side effects of the drug to help you determine which are likely caused by the drug.

The agency cannot prescribe a specific treatment for you. Only doctors who have examined you can do that. What the agency can and may do is specify what sort of doctor should treat you.

## **Finding a doctor**

You must use a doctor who is acceptable to the agency. They will not accept a chiropractor, herbalist, homeopath, and such. Some agencies will accept a naturopath (ND) or naturopathic physician (NMD), especially agencies located in the western USA.

The SSA will only accept MDs, DOs and psychologists, as far as we know.

You may have to try several doctors before finding one who will work with you. Ask for a referral from other people with the same disability in the region you live in.

Many people have had to travel hundreds of miles to see a doctor who accepts environmental illness. They mostly do phone or video consults, but you may have to visit in-person once a year.

If the agency gave you some sort of psych diagnosis, you may be allowed to use a psychologist instead of a psychiatrist. A psychologist cannot prescribe drugs, the treatment is only talking.

### **Be prudently cautious**

People seem to expect disabled people to sit and watch TV all day. You are allowed to have hobbies, but think about how your activities can be interpreted by people who do not understand what living with the illness is actually like.

There have been cases where the disability agency hired a detective to spy on disabled people to see if they are malingerers. This seems to be rare, and only in the first years of disability.

There have also been cases where people have complained that their neighbor seemed too functional.

We have a collection of entrapment stories in a separate document, which is available through the link at the bottom.

Be prudent about what you share on social media. Some people can get upset that a person receiving government money goes on vacation or sits on a beach. Be cautious about what pictures you post.

Artificial intelligence will likely soon make it very cheap to monitor everyone who receives disability benefits.

A neighbor who sees you work on your house may not understand that you use non-toxic materials and have full control over the worksite, as opposed to if you were hired to do such work.

Again, you are allowed to have hobbies, it is just difficult to know where the line goes for someone trying to entrap you, or some outsider who is clueless about what living with the disability is really like.

## **Doing volunteer work or activism**

Volunteer work, including activism, can be an excellent way to break the social isolation and get a sense of having a purpose in life. It can also prevent depression, which is a common side-effect of being disabled.

But be careful, as it may trigger a review of your disability benefits, if it appears that you are working a lot of hours every week, or what you do is physically or mentally demanding tasks.

If you do volunteer work for a business, especially one owned by a relative, that doesn't look so good.

The disability agency may terminate your benefits if it looks to them that your volunteer work shows you are able to do paid work. (Perform "substantial gainful activity" as the SSA words it.)

Unfortunately, the government and private agencies we checked did not have clear guidelines on how much volunteering is acceptable to them. You may want to see if your agency has guidelines posted on their website (best not to call or e-mail such a question, as they may store a record of it).

Some disability attorney websites suggest not doing more than "a few hours a week." And not do work that otherwise could be paid enough to make a minimal income.

We are not aware of any activist who was harassed by a disability agency because of their activist work. This despite some of them doing amazing work over many years.

## **If you are getting better, but not ready to go back to work**

Some disability agencies (including the SSA) have programs that help people get back to work gradually, over a couple of years or so.

The agencies do these programs hoping to get people off their payroll, so they have reasons to do them well.

The SSA's program is called Ticket to Work. It is voluntary, flexible, and comes with some carrots to get you to sign up. That includes no reviews of your case while you are in the program, and you can stop anytime. They also provide a lot of practical assistance. The requirements for staying in the program are flexible.

If you are getting better, but not fully well, such a program may be for you. You can use it to postpone the next full review if you think you may not pass it, but you are not actually ready to go back to working. You can also use it to find out whether you can work, without having to commit to working yet.

**More information**

More articles about disability benefits on [www.eiwellspring.org/disability.html](http://www.eiwellspring.org/disability.html).