



Solve M.E. Patient and Caregiver Resource Guide: Navigating the Disability Process

One of the most horrific effects of ME/CFS or Long Covid is the inability to work, and the often-crippling loss of income. If you are unable to work, or if you feel yourself struggling to continue to work, do not hesitate to file for disability insurance. The time from applying for disability to the time of approval can take from six (6) to twelve (12) months, or longer.

There are multiple sources for disability insurance in the United States. Some large corporations provide disability insurance for their employees, and private disability insurance can be purchased from insurance agents – prior to the onset of illness. A few state governments provide disability insurance payments for their government employees, and the federal government provides two types of disability insurance.

Social Security Disability is a federal program administered by the Social Security Administration. It provides benefits to persons who are totally disabled, unable to work. Social Security Disability has two programs, SSI and SSDI.

SSI (Social Security Income) is a program designed to assist low-income persons who may have never worked, or have not worked enough to earn sufficient work credits for SSDI.

SSDI (Social Security Disability Insurance) is funded by taxes, so only persons with a work history are eligible. To receive SSDI, your application must show that you can no longer work in your previous occupation, you cannot adjust to a new work environment, and your disability prevents you from being able to return to work for at least a year.

Don't feel that you do not deserve help, or feel like it is a weakness to ask for help. Reluctance will only prolong the pain, both physical and financial.

There is paperwork to fill out for any type of disability insurance you select. For federal assistance, you mostly likely will be denied approval on your first attempt to gain disability insurance. You will probably need to appeal the decision multiple times. You are given the right to appeal, and you should accept that right, as part of the normal process.

After you have filed your appeal, you will typically be offered a hearing in front of a federal administrative law judge. One of the most important factors in going in front of a Federal Judge to request disability insurance is hiring a competent disability attorney who is also respected by the federal courts. You should ask attorneys you may know and respect for a recommendation. You can also review the American Bar Association website for disability attorneys in good standing. Try to obtain a recommendation specifically for an attorney who is located in the region where your federal court is located. Many judges at every level in the court system may be more amenable to local attorneys with whom they are familiar, than they are with attorneys from outside their jurisdiction. Research the percentage of their win/loss cases for ME/CFS or Long Covid.

Documentation for Disability Hearings

It is imperative to get information for your hearing collected and collated into a structured format. Judges and attorneys need information and education about your life prior to the illness, about the illness itself and how the illness is currently impacting your life.

As you begin this most arduous task of collecting information for the hearing in your weakened state, You Must Ask for Help! Your Personal Support System can assist you by picking up requested medical information, making copies, helping you compose letters, and by driving you to and from appointments. You can be the organizer of your plan. You do not have to do all the work yourself. Select the

time of day when you are at your best, and work in short spurts during that time. If you have increased symptoms on any given day, take the day off. Everyone takes time off when necessary. Don't beat yourself up if you need to take a day off to rest your body and your mind. Just get back to it when you can. Readjust your timeframe as necessary. Keep moving forward. Be kind to yourself!

Get prepared to help professionals you are asking for help. Be as specific as you know how to be, when asking busy professional persons for a letter or documentation for a court hearing. While their honest input may be that critical piece that could make a huge difference in your life, it is often an extra chore for them.

You are allowed to have witnesses testify at your hearing. Your attorney will decide if it is best for you to testify, or not. If you are allowed to give verbal information, paint a picture of what you looked like prior to the illness. Then paint a picture of what your functioning looks like currently, and what symptoms keep you from working. Even if you have a symptom of cognitive disorder (brain fog), do not hesitate to present verbal testimony. If "brain fog" occurs naturally during your testimony - simply point out the symptom and move on. Do not be embarrassed and try to cover it up. It is part of your current picture. You need to allow it to be viewed by others who are attempting to make a decision in your case.

Disability Hearing Checklist

- Research potential disability attorneys
 - Date completed:

- Recruit a friend or family member to help you with all disability tasks
 - Name:
 - Contact Information:

- Date completed:
- Hire and meet with selected disability attorney
 - Name:
 - Contact information:
 - Date completed:
- Compose a letter for your doctor with facts about how your illness has and is currently affecting your life
 - Date completed:
- Request a personalized letter from your doctor, incorporating information from your previous letter, plus
 - Medical tests
 - Medication trials
 - Clinical trials
 - Progress notes
 - Laboratory reports
 - Other Medical records: _____
 - Date completed:
- Research and obtain educational information about your illness to present to your disability attorney and trial judge
 - Date completed:
- Collate and organize all information gathered and forward to your attorney
 - Date Completed: