

Tactics for SS Disability

By Debra Sjolseth

Note: RSDSA received this letter about SS Disability, and we thought it would be helpful to our readers.

Thanks for the SS Disability Help

I was able to get Social Security (SS) Disability the first time I applied because of this site! The state assigned me a caseworker. I explained my condition and gave him the code so he was able to find it in his book of covered disabilities. It helped him understand it better too. So I just wanted to thank you so much!

Now, I'd like to share with your readers a little more information regarding getting on SS Disability to help make the process easier for others. Just because CRPS is a covered disability, doesn't mean you are approved automatically. You need to show why you can no longer work, full-time or part-time

1. Give your assigned caseworker the disability code for CRPS, which you can get from the <http://www.rsd.org> site. He or she will be able to familiarize themselves with the syndrome by reading about it. Then refer them to two sites for additional information: www.rsd.org and <http://www.rsdhope.org>. Be sure you write both of these sites on your application as well.

Start a three-ring binder, immediately. Keep a running log of appointments, newspaper and Internet articles, changes in your ailments, etc., like a diary. You'll refer back to it over and over. Include photos of your body and show how CRPS has affected you, if it can be seen. Put info that you find along the way regarding CRPS into your binder and carry it with you to all doctor appointments.

Most physical therapists don't have a clue about CRPS, so print out a few copies of the brochure especially designed for them (you'll find it on www.rsd.org) Also, give your doctors a copy of whatever you want them to have, such as photos of my ulcerated foot throughout the process.

My family nurse practitioner told me "This is YOUR illness not mine. Take responsibility for it. Learn about it. Read about it. Get educated. I cannot in a 20 or 30 minute appointment tell you all about your problem."

It was great advice!

2. You'll need to prove that you cannot stand or sit for more than an hour or two at a time because, in my case, my ankle swells terribly and has to be elevated. I told my caseworker I have to lay down with my foot elevated, and it is hard to find a decent job lying on my back. He thought that was funny.

3. I got my Podiatrist-Surgeon-Wound-Specialist doctor to write a letter to the caseworker that confirmed the above. He also said it will never get better and he considered me totally disabled without a chance for recovery. (Of course, we know it could go into remission but it's not something you want to put down on paper, it confuses them.) The two most important parts of the letter were the amount of time I could have my foot down and there was no chance for recovery. The maximum amount of time could be no more than one to two hours, I was told otherwise they'll have you work sitting down somewhere at least part-time. He also said I was unable to walk any distances or stand and that if I did, my foot would swell and more ulcers would form from splitting or leaking skin. So I needed to continuously change from sitting, laying down, and standing.

4. I also got a letter from my pain specialist, who is a dispensing nurse practitioner. She specializes in pain management and really knows her drugs. She is the best by far of all the medical personnel I have seen for my CRPS. She works in a family health care clinic and not one of the Pain Management Clinics. I have been to two of those. They are expensive, refuse to fill out any forms, will not write a letter on your behalf, and have their noses in the air. They act like every one of us is only out for drugs. In contrast, my Dispensing Nurse Practitioner (DNP) is kind, caring, more knowledgeable, respectful, and works harder. I would recommend everyone find someone like her. They are out there and usually a Nurse Practitioner or Physician's Assistant.

5. My assigned case manager said he wanted me to see their doctor. I asked him where and he told me. I looked it up in the phone book and discovered there were about 10 doctors at this pain management building and they do the evaluation regarding how much you can lift, etc. They have to break it down in percentages. I called the business and asked the appointment maker if there were other doctors there who could do the disability evaluations because not everyone is licensed to do them. Seven or eight of the doctors there did the evaluations. I also asked about the doctor that SS Disability wanted me to see, and what percentage of her business came from SS Disability. It was about 80% or 90%.

Well, that told me right there, that the SS Doctor wants to please her meal ticket, so there was no way I was going to see her. I called my dispensing nurse practitioner (DNP), who recommended two physicians in that practice. Then I called my case-manager back and told him, "I've decided I want to see someone other than the doctor you asked me to go see" and I told him why. I didn't lie. I said put yourself in my shoes. Would you want to see her? I told him I would see any other doctor in the same business, just not her.

First, he said it would take some time because he would need to find out if these doctors even do SS Disability Evaluations. I told him I had just spoken with the woman who makes the appointments for them and she knows who does what. Then he said, he didn't know if you can request a particular doctor and that he had already set the appointment and sent them the paperwork. I said I was sorry but it just had to be changed. He said he would get back to me and he'd have to go talk to his supervisor. I waited all day and when he didn't call me back at 10 minutes to 5 on a Friday, I called his supervisor, who said, "I told him it didn't make any difference which doctor you go to. Didn't he call you back?"

There was more to this story, the case manager also lied and said they have to prepay for the appointment and he didn't know if he could get the money back or transferred to one of the two doctors I wanted to see, but that was a lie. He was just trying to get out of correcting the paperwork with a different doctor's name. Too bad, I caught him in his lie and mentioned how sorry I was about the prepayment problem when I spoke to his boss and he asked me what I was talking about. I told him of the conversation and he said he would straighten it out.

6. Lastly, I took pictures all along the journey. I took photos of my CRPS affected areas. Sometimes they were photos in a full length mirror, sometimes the mirror over the bathroom sink, and sometimes of just the affected area with something next to it to give it a size. My ankles really swell so I had pictures of them. I also took photos of my ulcerated heel with a little piece of paper taped on it with the date and a coin of some relevant size. They started out as half dollars, then quarters, then pennies.

The photos were a great asset in showing it to the caseworker and to the people at the end of the line to whom the caseworker sends the report. By the way, my caseworker at first led me to believe we needed to please the unknown people who would be receiving my application out of state, so that's why the wording on the doctor's letters, etc. were so important. But in the end, he told me that he and his boss are actually the decision makers and the people out of state always go with their recommendations.

Your caseworker knows if you'll get it or not. He also said if most applicants were as involved or interested it would make his job so much easier. He said about 20 to 30% of the time, the applicants don't show up for their social security doctor evaluations. Please go to your social security disability doctor evaluation!

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