

CHAPTER II

Social Security Disability Insurance and Supplemental Security Income: How to Jump Through Hoops Without Stumbling

Peter H. D. McKee, J.D. and Alan Wittenburg, MSW

APPLYING FOR SOCIAL SECURITY?

For some of you, there may come a time when you conclude, often reluctantly, that you should apply for the disability benefits that are available from the Social Security Administration (SSA). Your decision to apply or not, and the impacts of your decision, can have long-range effects, both positive and negative. Legal, social, medical, vocational, financial, and emotional considerations must all be weighed when deciding whether to apply for Social Security disability benefits.

It might seem to you that applying for these benefits requires conquering seemingly insurmountable barriers of bureaucracy, delay, medical, and legal processing. However, with some knowledge of how the system works, and a strong sense of determination, along with the help of your friends, relatives, doctors, and other healthcare providers, this is an effort worth pursuing. What follows is intended to give you some starting tools to help you pursue your claim more effectively. Because this topic is vast, this chapter can provide only brief summaries of some of the important issues to consider when you apply for Social Security disability benefits. More information can be obtained from the resources listed below.

A Short List of Resources: Social Security Disability Claims

Social Security's own web site. See the Resources section in the back of the book. The link will connect you with an enormous collection of information about the rules, regulations, and other matters related to claims for both disability and retirement benefits.

The National Organization of Social Security Claimants' Representatives (NOSSCR). This nationwide organization of lawyers and other advocates representing claimants with disability for Social Security benefits is a valuable resource. Many experienced lawyers handling these cases are members, and NOSSCR has a nationwide referral program to help you connect with an experienced practitioner. See the Resources section in the back of the book for contact information. You can contact NOSSCR at 560 Sylvan Avenue, Englewood Cliffs, NJ 06432, 800-431-2804, email NOSSCR@worldnet.att.net.

Be aware, however, that merely applying for disability benefits with the Social Security Administration, or simply carrying the diagnosis of multiple sclerosis, does *not* entitle you to an automatic grant of these benefits. These must be understood as merely the starting points in the undertaking of proving your eligibility for the available benefits. It is only with knowledge of the system and proof of the severity of your MS that you will have the best chance of winning your claim.

Note: *In the fall of 2003, the Commissioner of the Social Security Administration announced a comprehensive plan for major revisions of the way Social Security processes disability claims. These plans intend to alter many aspects of the applications and appeals process at all levels. The specific details of these plans, and when and how they will be implemented, are still being developed. Thus, some of what is described in the following materials may have changed to some degree in the past several years.*

BASIC FACTS YOU MUST KNOW ABOUT THE SOCIAL SECURITY DISABILITY SYSTEM

The Social Security Administration is a federal agency under the umbrella of the Department of Health and Human Services. This department administers two disability programs: Social Security Disability Income benefits (SSDI or Title II) and Supplemental Security Income (SSI or Title XVI).

Social Security Disability Insurance (SSDI) Benefits

Social Security's disability insurance program requires you to show that you are (1) *disabled* (as defined by Social Security) and (2) that you have worked and paid into the Social Security system by paying your insurance premiums. The way you paid your premiums was by having a work history and having paid your FICA taxes in the past. If you have never worked or paid FICA, you will not be eligible for these benefits, as you have not paid your insurance premiums.

Adult workers who seek SSDI must show that, from the date they first became disabled, they had paid into the Social Security system by working and paying FICA premiums on adequate earnings in five out of the last ten years (or twenty out of the last forty work quarters). Special rules apply to workers younger than thirty-one as to how many quarters of work they must have had to become eligible for coverage. Thus a claimant under age thirty-one must show that he or she worked and paid into the system for one-half of the quarters between the time the worker reached age twenty-one and the time the

worker became disabled. For these reasons, *the date that you claim you became disabled can be critical in determining whether or not you have had sufficient earnings to be eligible for the insurance coverage.*

Supplemental Security Income (SSI)

Social Security also administers a second disability program called Supplemental Security Income (SSI) benefits. This program is similar to a public assistance disability program, in that you must show that you are disabled and that you have very little income and resources. To meet the financial eligibility requirements, you must show that you have no more than \$2,000 in “non-exempt resources” as an individual, and that you have a very low income. The regulations regarding what resources are exempt are quite complex. As an example, such items as the house you live in and one car that you drive will not count toward the maximum resources you are allowed to have and still be eligible for SSI.

It is possible for you to receive both SSDI and SSI, depending on your benefit level when you are on Social Security. How much you will get per month if found eligible for Social Security Disability Income depends on your past work history. At the present time (2005), the maximum Social Security disability benefit payable to a single individual is approximately \$1,825 per month. The maximum SSI benefit for an individual with no other income is approximately \$579 per month. Annual cost-of-living raises are applied to these maximum amounts.

With both the SSDI and SSI disability programs, you will also be eligible for medical coverage. Medicare is the medical coverage that comes with SSDI, but its coverage starts two years *after* you are determined eligible to receive your first monthly benefit. Medicaid is the medical coverage that comes with SSI in most states (in California, Medicaid is called MediCal). At the present time, only Medicaid provides reliable payment for medications.

Definition of Disability

At the heart of both disability programs is Social Security’s definition of disability. Social Security’s concept of disability is difficult to comprehend until you realize that, although they use the word that is found in the English language and is pronounced like the English word “disability,” Social Security’s use of the term can best be understood as a unique foreign language. Only when you understand this can you work effectively with the definition to your advantage.

Social Security defines *disability* as follows:

“. . . The inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last a continuous period of not less than twelve months.”

Do not fight this definition, *but understand it and learn to use it!* Put simply, and in a possibly overstated fashion, what you must prove with your medical evidence to be eligible for disability benefits is that, *if you were hired to do any job that exists in a significant number in the national economy, you are unable to do any full-time job in the national economy on a reliable and consistent basis.* Whether you have ever done the work, or whether the employer would actually hire you, pay you enough, or that you would want to perform this job is largely irrelevant. In any claim for disability you must address the question of whether you would be *able* to do any kind of work *on a full-time basis*, six to eight hours a day, five days a

week. Thus, questions of stamina, reliability, physical/cognitive issues, and ability to handle the reasonable expectations and demands of any employer should clearly be addressed.

As you get older, starting at age fifty, and definitely by age fifty-five, Social Security's assessment of disability will also consider your age as another factor in determining whether you are disabled. Because the decision of whether or not you have "proven" your disability can be made only by the Social Security Administration, a brief written declaration from your doctor declaring that "My patient is totally disabled" is not good enough. However, when that same conclusion is thoroughly documented by your doctor (e.g., your primary care physician or your psychologist), with the medical records that provide a complete history of your doctor's findings and an assessment of your symptoms, then such a letter, with supporting records, could go a long way in ultimately proving your disability, as defined by Social Security.

Information from a certified vocational rehabilitation counselor (CRC) related to your lack of employment potential or to your specific workplace challenges can also be helpful.

Note: Social Security has published a list of impairments with specific clinical findings, which, if medically proven, would entitle you to be found "disabled." (See appendix D-1 for the Listing of Impairments related to MS.)

UNDERSTANDING AND SURVIVING THE APPLICATION/ADMINISTRATIVE PROCESS

When you apply for disability benefits with the Social Security Administration, you can best understand the process you will be engaged in by thinking of it as climbing a ladder. At the top of the ladder are the benefits you seek. It is a very tall ladder with many different rungs, each of which must be used to climb to the top. There is no elevator to the top, and you cannot skip any individual rung. If you are denied at one of the rung levels, as a rule, you should promptly climb to the next rung by appealing that denial rather than dropping your efforts, jumping off the ladder, and starting all over at the bottom. Most importantly, at *every stage* of the administrative process, you normally have only *sixty days to file an appeal* of a prior denial. Do not miss this sixty-day window, because then you will have to start at the bottom rung of the ladder all over again.

Initial Application and Reconsideration

To start your claim for disability benefits with the Social Security Administration, you must file an application. This application process is the first rung of the ladder that must be climbed. *All* applications are made in writing, although frequently you will be asked to provide information over the phone.

After the initial phone interview, a final "hard copy" of that interview will be sent to you to sign and return, along with other papers that might need your signature. These might include release forms so that Social Security can get your medical records. Any additional information you wish to provide is supposed to go through the SSA interviewer who will mail additional information to the Disability Determination Services (DDS) Adjudicator.

In *all* of the numerous forms and papers that you will need to complete and sign, you should be "bluntly and graphically honest" about *all* of the medical, physical, and psychological symptoms that you and/or your friends say "affect" your ability to work. Leaving information out because of personal

embarrassment (or modesty) is the easiest way to make sure that the Social Security Administration does not completely assess your claim. We understand that it can be embarrassing for many of you to admit to memory problems, cognitive issues, or bowel/bladder challenges but this is critical information in assessing your ability to work.

It is important for you to make sure that your medical providers and counselors support your claim. If you believe that your MS is so severe that it meets Social Security's standards of disability, but your doctors and counselors do not agree with you, your chances of winning your case will be seriously reduced. Although the Social Security Administration is "supposed" to obtain the records from your medical providers, be aware that it is *your* duty to prove your disability. So, if you can get copies of your doctors' or counselors' records and letters that address your medical limitations and present these to the Social Security Administration, you will then know this information has been obtained and provided to the SSA. Do this as early in the process as possible because it can be difficult to get both clear and appropriate letters within the necessary time frame. Be sure to keep copies of all the papers you gather together and send to Social Security.

Once Social Security has reviewed all the information supplied, they will make a decision known as an *Initial Determination*. You will receive this as a written determination. Usually, this letter doesn't go into great detail about Social Security's analysis of the medical information. Frequently, it is so superficial that it may cause you to become frustrated and angry. If their first decision is a denial, instead of becoming frustrated or angry you should become even more determined.

Within sixty days of the date of the initial determination, you must climb to the next rung of the application ladder by *filing, in writing, a Request for Reconsideration* of your denial. All interactions with Social Security should be *in writing, submitted well within the sixty-day deadline*. If you are late, by even one day, Social Security can outright deny your entire claim. *Don't give them this easy out*. You should adopt the reliable strategy of submitting all papers to the Social Security Administration either in person or by certified mail, return receipt requested, and always keeping a copy of every paper submitted in an organized file.

At the reconsideration level, a second look at your case will be made, and you have the right to submit updated medical information. Remember, *always appeal an unfavorable decision well before the expiration of sixty days*.

If a second denial notice is issued, it may be captioned "Notice of Reconsideration." Once again, to protest the unfavorable decision at this level, you should file a protest within sixty days, this time by requesting in writing a *Request for Hearing*.

Administrative Hearing

The next rung to climb of the administrative appeals ladder will be a live, in-person hearing before an administrative law judge. **Note:** Currently, in many hearing offices, Social Security is experiencing delays of *nearly two years* from the time you request a hearing to the date of the actual hearing. Although these hearings are somewhat informal, and no opposing lawyer or jury is present, appearing before any judge can be somewhat intimidating. It is likely that this will be the first time you are face-to-face with the person making the decision in your case. It is not uncommon to find that the judge has called a medical and/or vocational expert to testify and express opinions about your disability.

Also at this hearing, the judge will be applying an enormous set of rules and regulations (about which you will know very little) to your case. The hearing gives you your best opportunity to present in your own words, and possibly brief testimony from your witness, how your medical symptoms prevent you

from doing all types of work on a reliable and consistent basis. Although the hearings typically last only for an hour, brief testimony from lay witnesses such as friends or relatives can play a critical role in confirming your limitations. Arranging the live medical testimony of your doctor or another specialist (e.g., your vocational rehabilitation counselor) could be quite helpful, but this can be difficult to arrange due to busy schedules. However, accurate letters from your doctor or counselor can suffice.

An administrative hearing before a Social Security judge might be compared to driving in the Indianapolis 500 car race. The fact that you have a driver's license and have been driving for twenty years doesn't necessarily prepare you to drive in that race. Similarly, the fact that your education and experience have stood you in good stead in your private and professional life doesn't make you a lawyer skilled in the critical nuances of a Social Security disability hearing. Finding and hiring an attorney who has experience representing people like you on a regular basis before Social Security hearings is quite important.

Find an Attorney to Help with Your Social Security Claim

Most experienced lawyers take Social Security cases such as yours on a contingency basis. This means that the lawyer seeks no payment for his or her time unless he or she succeeds at getting you your benefits. Usually, the lawyer's agreement with you will be that he or she is to be paid 25 percent of the retroactive benefits paid to you *only* if you are awarded benefits. All attorney's fees to be charged must be approved by the Social Security Administration, even if both the lawyer and the client have agreed to the fee. If you cannot find a local experienced lawyer to represent you, consider contacting the National Organization of Social Security Claimants' Representatives (NOSSCR). You will find the Web site for NOSSCR listed in the Resources section at the back of the book.

If you haven't consulted a lawyer previously, you should contact a lawyer immediately when you receive a second denial at the "Reconsideration" level. The Social Security Administration maintains a listing of lawyers' organizations who do this type of work—and your local MS organization will also know of attorneys in your area who are familiar with both MS and this process.

Note: Remember to file your hearing request well within the sixty-day time limit, even if you haven't been able to contact a lawyer.

Post-Hearing Appeals

In most cases, your judge will not announce his or her decision at the end of your hearing, but will take the case "under advisement," and issue a written decision several weeks to a few months after the hearing. If the judge's decision is unfavorable, further appeals may be taken to the Appeals Council in Falls Church, Virginia, by filing a "Request for Review of Hearing Decision" within sixty days. Unfortunately, delays of more than a year and a half at the Appeals Council are quite common.

Federal Court

If your case is again denied by the Appeals Council, you have sixty days to file a formal appeal in your local federal district court. You should be aware that most lawyers are hesitant to take on new cases for the first time after they have been denied by the Appeals Council because the lawyer has had no input

into the preparation or presentation of the case up to that point. Any federal court appeal will be limited to the records presented up to that point. Your best chance to win your case requires the presentation of a comprehensive claim for benefits through a team effort headed by you and supported by your family, friends, healthcare providers, and, at times, your lawyer early in the administrative hearing phase.

When Should You Apply for SSDI/SSI?

The answer to the question posed above is that it really depends on your individual circumstances. As discussed in chapter 8, perhaps you can continue working if your employer can provide you with reasonable accommodations. If you believe that you need to consult with someone about whether your needs can be met by seeking reasonable accommodations, consider discussing your concerns with a neurologist, vocational rehabilitation counselor, or other rehabilitation specialist. Your local state vocational rehabilitation agency or multiple sclerosis organization can also be helpful.

If, however, accommodations were tried and are no longer helpful, or accommodations were not applicable in the first place given your situation, it is probably time to apply for SSDI.

The Social Security Administration has determined that if you are able to earn at least \$830 per month (2005 figure), you are not considered disabled by their definition. So, you may ask, “Can I apply (and not be immediately disqualified) for SSDI and still work, as long as I earn less than \$830 a month?” The answer to that is a very unreliable “yes,” although others may disagree with that. Regardless, you definitely will need to have very strong, accurate, detailed documentation proving that the amount of work you are currently doing is the maximum you can do.

SOME PERSPECTIVES ON THE PROCESS

Sources from which you will need to obtain strong disability documentation include your neurologist or MS specialist, a vocational rehabilitation counselor, or other specialists/professionals with whom you may be working and, hopefully, your employer. Remember, you are claiming that due to your disability(ies), you cannot work at any kind of “full-time” job based on the criteria for “substantial gainful activity.”

Swallow Your Pride: Don't Try to Do It All by Yourself

If you don't feel overwhelmed by the application process, then you don't really understand it!

Putting Your Team Together

Your team *must* consist of medical personnel, especially a neurologist and, if applicable, your primary care physician, rehabilitation counselor, neuropsychologist, rehabilitation therapist(s), psychiatrist, and so on. Getting a support letter from your neurologist and other applicable medical people who have treated you recently can be a crucial supplement to your medical records. (See appendix D-2 for sample letters.) Because MS is a disease of the central nervous system, a board-certified neurologist's opinion is given greater weight by the SSA and its courts than an internist's or other medical person's opinion. However, the opinions of your doctors, no matter what their specialties are, must be given great weight by SSA.

Make sure your doctor and therapists have pertinent information in your medical charts because they will be requested by the DDS Adjudicator.

For example, have your telephone conversations with your healthcare providers been entered into your medical chart and if so, do you know what they say? Also, do you know what was added to your chart during your regular office visits? Have you been candid with your doctor about how you are really feeling and functioning: physically, cognitively, and emotionally? If you haven't been candid, begin doing so now. If you have been open and honest about the state of your health, then ask to see your chart to make sure you know what's in it and to make sure the information is accurate.

Note: The support letter from your physician to the Social Security Administration is the most significant. For that reason, make sure that your doctor's letter to the SSA contains all of the information listed in checklist 12 below:

Checklist 12: Your Physician's Letter

- ___ His or her accreditations and/or credentials and signature appear on any correspondence to the SSA
- ___ What your formal diagnosis is and the date of your diagnosis
- ___ When your symptoms started to occur
- ___ How MS limits your activities and how it would limit work-related activities (provide the doctor with a description of your job and check off the job tasks or functions that are limited by your MS). It can also be helpful if your spouse (or significant other) and your vocational rehabilitation counselor write a letter on your behalf noting observations they have made about your limitations. That is, they can check off tasks or functions that are difficult or impossible for you to perform. This would include both daily activities like dressing and housekeeping, and work activities like typing, planning, remembering, organizing, and so forth. It is important for your doctor to refer in the support letter to how each of these types of activities is compromised because of your disabled condition.
- ___ What your medical tests have shown
- ___ What treatment(s) you have received including what worked and what didn't work
- ___ Your likely medical future (this information is of critical importance to the SSA)

Cognitive and Emotional Issues

If your symptoms include cognitive and/or emotional issues, and you have seen a neuropsychologist and/or a psychotherapist or other type of practitioner for these problems, having that practitioner write a support letter for you can be very helpful. Most people with MS have stopped working more because of their cognitive problems than because of their physical or emotional issues. Allow us to repeat ourselves: We know that it can be hard to be honest about (or even to understand) lapses in memory and problem-solving skills, or other issues involved in thinking clearly. But this is not your job. This is the role of the neuropsychologist.

A support letter from the neuropsychologist who did your neuropsychological evaluation can be critical. Ideally, the letter needs to include the elements listed above along with a summary of the results from the testing (a four- to eight-hour battery of tests) and what conclusions can be made in terms of your ability to work at substantial gainful activity. (See chapter 10 for a complete discussion of neuropsychological testing.) Likewise, if you have been seeing a psychotherapist, a support letter from him or her can also be helpful and should include the elements listed in the checklist above. Often, your neuropsychologist can also address your emotional issues.

Former Employers

Sometimes, your former employer(s) will be willing to write a support letter on your behalf. He or she can attest to the functioning problems you were having that affected your ability to work. This can range from attendance and dependability issues to productivity and quality of work. Needless to say, this may be the only time when information about your getting fired, laid off, or having resigned from a job can actually help you. If a former employer is not willing to write a letter or you're not comfortable asking him or her to do so, attach a copy of your job performance evaluations that indicate problems and explain how these problems were caused by or related to your various symptoms. Some truly supportive employers may actually be good witnesses for you at a hearing.

Emotional Support

Okay. Touchy-feely can be good. It can be very helpful to secure everyday emotional support and assistance. But, it can be absolutely critical in helping you through the very personal and difficult Social Security application process for a variety of reasons. One such reason is that during this application process you will need to acknowledge the many losses you've suffered due to the MS and how it has impacted not only your ability to work, but your entire life. It can also be helpful if your psychotherapist, significant other, or friends write a letter for you documenting the emotional stresses you are experiencing.

Hands-on Assistance

Lastly, if available, an MS social worker or counselor knowledgeable about the process of applying for SSDI and SSI and what the Disability Determination Services Adjudicator looks for in answers to the application questions can be instrumental in helping you to win your claim. You may receive an offer from the Social Security intake person or from an SSI facilitator to help you fill out the application form. Thank them for their offer, but do it yourself with your own advocate or team. You and your team have far more incentive to do a comprehensive and well-written application than a Social Security Administration employee or state employee.

Applying for SSDI Is Your Full-time Job

You have now embarked on a real, frustrating, demanding, and time-consuming process. Expect to spend eight to twelve hours minimum engaged in the following tasks:

- setting up your team,
- coordinating their separate pieces of documentation,
- gathering pertinent information,
- doing the prep work,
- drafting comprehensive and concise answers to the questions on the application form,
- reviewing your answers until you and your team are satisfied,
- writing a cover letter stating what attachments you are including,
- making copies of everything you plan to send to SSA by certified mail (or bring to the SSA interview), and then
- sending it.

Note: An experienced MS advocate should review all of your responses to application form questions before you give your application form to the SSA.

Prepare Yourself Mentally for This Endeavor

This is not the time to make the best of a bad situation. For the next few weeks, filing for SSDI will be your “job.” Do not pretty things up. It is crucial that you be honest, objective, and forthcoming about the severity of the symptoms that cause your inability to work at substantial gainful activity (SGA). This means *all* of your applicable symptoms including very personal and perhaps embarrassing ones. This is not a time to tone down what is really going on. Be blunt and graphically honest about the full range of your symptoms and limitations.

Prepare Emotionally for Saying What You Need to Say

Think of the well-known Native American saying: “Walk a while in my moccasins before you judge me.” You want the person who will review your application to be able to walk in your shoes twenty-four hours a day, seven days a week, based on the information you provide. Your objective is to separate you, the unique individual, from the you who is the applicant who deserves these benefits. The challenge to you and your supporters is for you to become one of the 30 to 35 percent of applicants who win their claim the first time around.

To do this, you must be honest with yourself and acknowledge all the symptoms that have a negative impact on your daily activities and your ability to work. You must also be willing to accept what people close to you have observed about any cognitive impairment you have demonstrated, as an example, and include this in your application. This type of impairment can be documented in letters from several of your friends. If their observations can be medically or psychologically documented, then you would want to include this documentation in the appropriate section on the form. Again, this is not the time to put your best face forward. Be completely truthful about all of the limitations you’ve had to endure.

HOT TIPS ABSTRACTED FROM THE SSDI TUTOR*

by Rebecca Pursely

Do Your Homework

Before contacting Social Security, you should gather all of the necessary information you will need to fill out the application form and get a strong rough draft completed. Once you have done this, then contact Social Security and officially begin the process. Once you contact them and get into the system, the clock starts ticking for when you must have it all turned in. Although they won't tell you this, you actually have six months to complete the application process. Naturally, however, you don't want to wait that long. On the other hand, you don't want to feel the pressure and stress of being given an arbitrary deadline by the Social Security people.

McKee's Twelve Rules for Dealing with Bureaucracies

1. **Get and stay organized.** Do not rely on Social Security (or any other bureaucracy) to keep track of your papers, phone calls, and other contacts with them. Assume that they will lose things and you will have to prove that you filed critical papers on time. Keep copies of every paper you sign or give to Social Security. If mailing any papers to Social Security, send them by certified mail, return receipt requested, and staple the return card to your copy, which you keep in a chronological file.
2. **Name and number.** Whenever you talk to someone by phone, do not hang up until you have his or her name, address, direct telephone number, and if need be, his or her fax number.
3. **Says who?** When given an answer you think is wrong, confused (or you just don't like), politely ask for a copy of the written authority which is said to explain/justify/require the person's answer.
4. **Official policy ploy.** If the ultimate fallback position of the person you are talking to is that "official policy/office policy" is the basis of their answer, express your doubt about this answer, and ask to see a written copy of that policy.
5. **Call the boss.** For almost every person you speak to in a bureaucracy, that person has a boss or supervisor who may have a completely different (and possibly more favorable) answer to your request. Talk to that supervisor/boss. Keep climbing the ladder. When all else fails, if your claim is getting no action and has become "stuck" or "lost," consider contacting your local congressional representative. A congressional inquiry sometimes can "shake things loose," but it *cannot* affect Social Security's ultimate decision as to whether you are disabled.

* Acknowledgment—We thank Rebecca for the gracious use of her currently unpublished *The SSDI Tutor*, her participation as copresenter of the materials from her Multiple Sclerosis Association of King County's SSDI/SSI workshops over the past several years, and for her perseverance and dedication to helping others with their applications in spite of "bad days" with her MS.

6. **Document, document, document.** Assume that if it isn't confirmed by writing, and it isn't in your hand, then it doesn't exist. This applies to anything that people say has happened, say is going to happen, and to things that you say you have done.
7. **No snow job.** When someone gives you an answer to your question or request, don't say, "Yes, I understand," when you're really thinking "What the heck does *that* mean?" Make that person explain it down or up to your level. Work through the anger you may feel and persevere.
8. **Set a deadline.** When someone says he or she will get back to you with answers to your request, set a definite date for that to happen (at least in your own mind). When that date arrives, almost regardless of what has subsequently taken place, write *one* follow-up request, and then, if you don't receive a reply in a short period of time, assume that person will *not* do what he or she promised, and plan another strategy.
9. **Don't quit.** Be persistent. The main defense a bureaucracy has is its great ability to out-wait those who request it to take actions. Take a perverse pride in your ability to demonstrate greater stamina and tenacity than the bureaucracy personnel.
10. **Know when to quit.** There are times when you must drop your long-pursued approach to achieving your goals. It's okay to be determined, but it's not okay to become obsessed.
11. **Know the pros.** Maintain a list of names and phone numbers of the people in the bureaucracies with whom you deal who really know their stuff, have shown themselves to be caring and willing to do what they promise, and have a record of actually getting the job done. Be nice to these people, above all others.
12. **Be professional.** At all times, be professional, courteous, and honest. Your credibility in the entire application process is the key element to your disability claim.

Start a daily journal NOW! This can actually be used as documentation. Items to be documented include such things as the following:

- An outline of your activities on an ordinary day. Appendix D-3, the Daily Activity Questionnaire, can be helpful to review here.
- The location, duration, frequency, and intensity of your pain or other symptoms.
- The factors that trigger or worsen your pain or other symptoms.
- The type, dosage, effectiveness, and side effects of any medication.
- Treatments, other than medications, that you take for your pain and other symptoms.
- Name your worst/most troublesome symptom, then rate it on a nuisance scale from 1 to 10 each day. It can be helpful to utilize the rating scales you will find in appendix D-4.
- Keep a calendar by your bed and write "good," "bad," or "okay" on the date before you nod off to sleep.

Sample Journal Page			Day/Date:
Time	Activities	Pain Triggers	Pain Location, Duration, Frequency and Intensity (0–10) of Discomfort
7–8 A.M.			
8–9 A.M.			
9–10 A.M.			
10–11 A.M.			
11 A.M.–12 P.M.			
and so on . . .			
Medications and side effects:			
Other treatment:			
Most troublesome symptom(s):		Rating 0–10 as to discomfort	

Keep Records of Everything Related to Your Health and Disability

Phone calls. Record the (1) date and time of call, (2) the names of people you talked to, with (3) their titles, (4) affiliations, (5) phone numbers, and (6) conversation highlights. See the form below for a sample of how to document a phone call:

Sample Phone Call Documentation

Date and Time: _____ Conversation with: _____

Title of person you're calling: _____

Summary of Conversation: _____

Dates. Write the name of the item and the dates that you requested the item, received it, sent or delivered it, and followed up with a phone call, letter, or visit.

Letters, notices, and forms. *Keep all correspondence.* Register all mail correspondence you send to SSA or the DDS Adjudicator and write “return receipt requested” on the front of the envelope. Get receipts for all items you deliver personally.

Make two copies of all documents you send to SSA/DDS. Submit the original but keep two copies. One copy is for your reference so that you don’t contradict yourself if SSA/DDS requests more information. It can also be useful if you need to fill out any other type of insurance forms. The second copy is a spare in case your original disappears.

Prepare to wait. When you call SSA, expect to be on hold for annoyingly long periods of time, especially if you are calling the local office as opposed to the 800-772-1213 number. Anticipate a wait and plan something to do while you wait. If you visit a Social Security office, bring any medications you may need to take over the next three to four hours. Once you’ve submitted your application form, you will most likely be asked to submit additional information to complete your application. Once these forms have been turned in, it’s always a good idea to check back in a couple of weeks to make sure DDS received all the requested documentation and be sure to ask if there is anything else they need. After you have confirmed this, expect to wait two to three months for a decision.

THE NITTY-GRITTY: THE NARRATIVE SECTIONS

There are at least five questions SSA routinely asks for which you will need more room than the tiny spaces provided by the application form. These questions are as follows:

- An in-depth description of *what* your multiple sclerosis symptoms are and *how* they affect you.
- A detailed assessment of *how* your MS symptoms limit your ability to work at any type of job.
- A complete list of the job-related changes you had to make because of your multiple sclerosis.
- The specific reasons why you stopped working.
- A comprehensive review of the job you held the longest and the duties you performed.

This last question probably won’t be a problem to answer, although you can approach your answer by breaking down your job duties and responsibilities into three parts: the thinking part of your job (cognitive), the physical demands part of your job, and the emotional/psychological aspects of your job. The latter refers to the job stresses, such as supervising and/or interactions with coworkers, managers, or customers, deadlines, financial responsibilities, safety responsibilities, and so forth.

The first four bulleted items are a different matter. It is **very** important for you to be *thorough*, *comprehensive*, and *concise* in your answers. The following pages will help you by describing useful writing techniques and organizational strategies to employ. As Ms. Pursely says, “Yes, this is a *major* undertaking.

Yes, it is a pain. Yes, you shouldn't have to go through all this to get your own money. Yes, it stinks. And, yes, it's necessary."

Suggestions and Examples

Whenever possible, go for answers that create a clear picture of the point you're trying to make. Try to illustrate your point with comparisons or contrasts:

- *Example:* A year ago I averaged eight hours of sleep a night and took a daily half-hour nap. Currently, I need ten hours of sleep each night and I require a half-hour nap in the morning and an hour nap in the afternoon to be able to complete my day.
- *Example:* One year ago, I did all the shopping (twice a week), prepared dinners, and did the laundry and cleaning. Six months ago, I had to reduce this to shopping once a week, cooking every other dinner, no laundry, and cleaning only the bathrooms and kitchen. Today, I fix one dinner a week, and help only marginally with cleaning the kitchen. These changes have occurred because of my fatigue, pain, and balance problems.

You may also want to use "if/then" or "else" or "cause and effect" statements:

- *Example:* If I walk briskly for more than ten strides, then my legs become too weak to support my body.
- *Example:* I must hold on to the grocery cart at the store or else I fall into the shelves.
- *Example:* Riding in a car for longer than fifteen minutes causes my legs to go numb.

Organizing Your Narrative Answers

To help you frame your answers, see appendix D-4 for diary-format and applicable worksheets. Remember, the disability application form is for anyone who claims he or she is unable to work due to his or her disability or disabilities. As Rebecca Pursely says, "The challenge is to state your case adequately within a form that's better suited to a disease or condition with a single symptom." In other words, not multiple sclerosis.

There are four worksheets included in appendix D-4. Because fatigue is a major MS symptom, there are two worksheets especially for fatigue. The other two worksheets can be used to describe your other symptoms.

Note: There are four steps to filling out these worksheets:

1. Make a list of *ALL* of your symptoms. If you have more than one disease or condition, include those symptoms as well. Remember: *you* are applying, not your MS.
2. Make a copy of the worksheets in appendix D-4 for *each* symptom you have.
3. Complete the worksheets.

4. Use the information from page 1 of each worksheet to answer the questions on the application under Part 1 4A, where they ask you to describe your condition. Use the information from page 2 of each worksheet to answer the questions on the application under Part 1 4B and 5, where they ask you to describe your symptoms that affect basic work activities.

Cognitive and Emotional Symptoms

Leading experts in the field put the percentage of people with MS who do or will experience cognitive problems during their lifetime as a majority. Also, experts in the field indicate that the percentage of those with MS who do now or will experience depression in the future is extremely high, as are mood swings. What this means is that cognitive and emotional issues are not something you can ignore or should keep secret when applying for SSDI or SSI.

It may well be the case that a majority of claimants for Social Security disability benefits were forced to stop work because of their cognitive problems. If cognitive and/or emotional problems are part of the reason you are applying for either SSDI or SSI *and you state this on the application form*, expect to receive a notice from either the DDS or SSA that they will need to schedule you for an assessment with a psychologist.

They will send you to someone who has agreed to accept the amount of money the SSA will pay. Will that person have any experience with MS? It's doubtful. Will that person play a role in determining your fate? Absolutely! Therefore, when you receive notice from the DDS Adjudicator, call back, make the appointment, and, if cognitive impairments are your issue, be sure to send a written request for a full neuropsychological evaluation. They won't pay for a full battery of tests but they may well pay for a mini-neuropsychological evaluation. Even if they refuse your request and set you up for the traditional fifty-minute session, at least you will have documentation of what you requested. (Remember, you must keep two copies of everything you send to them.)

This may be helpful if you are denied benefits, and you appeal the decision. Ideally, you will already have had a full neuropsychological evaluation done by someone of your choosing via a referral from your neurologist/team, or you will already be seeing a psychologist or psychotherapist for emotional issues. Usually, but not always, a report by those treating you will satisfy the reviewer of your claim.

Conclusion

You have worked very hard over the course of your career and you were told that the money you put into Social Security was an insurance plan (financial benefit) for either the day you retire on your own terms or for the day you retire due to a disability. Unfortunately, too often the Social Security process for disability benefits has become an adversarial process. It is Goliath and you are David. Therefore, you need a team comprised of people who are informed, willing to help, emotionally supportive, and capable of assisting you through this arduous process called "Applying for Social Security Disability Benefits." You can triumph, but you must be very persistent and well-organized. Our very best wishes to you during this difficult process.