

A guideline for people and their healthcare providers on how to apply for disability benefits after a battle with superficial siderosis

# Social Security Disability Insurance

A Guideline for  
Superficial Siderosis Claims

SUPERFICIAL SIDEROSIS RESEARCH ALLIANCE



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## Introduction

The Social Security Administration (SSA) recognizes SS as a chronic disorder or "impairment" that could cause disability severe enough to prevent a person from working. Due to the severe progressive nature of the disease, in 2018, the US Social Security Administration added superficial siderosis to the Compassionate Allowance list of conditions that allows for the fast-tracking of disability claims. Any of the following (or other) SS symptoms may become severe enough to interfere with a person's ability to continue in the workforce:

- Difficulty with walking, maintaining your balance, or engaging in other physical activities
- Trouble using your arms, hands, and fingers to carry out tasks
- Impaired Vision
- Cognitive issues which interfere with tasks such as memory, attention, problem-solving, multi-tasking, processing, planning, and prioritizing
- Inability to function either physically or cognitively for prolonged intervals of time because of severe fatigue
- Breathing, speaking or swallowing impairment
- Diagnosed severe and persistent depression
- Severe and persistent pain
- Profound hearing impairment for those over 50

A person with superficial siderosis (SS) who cannot work for a continuous eight hours daily, for five consecutive days weekly, due to multiple SS-related impairments or other related conditions may qualify as permanently disabled.

The same medical criteria (See Appendix) apply whether a person is applying for:

Social Security Disability Insurance (SSDI): individuals who have worked for a sufficient period and have contributed Social Security payroll taxes (FICA )

Supplemental Security Income (SSI): individuals who have not worked or paid Social Security taxes but whose household meets SSI income levels.

## The Application Process

Applying for Social Security Disability is a complex process that requires a close partnership between you, the person with SS, and your healthcare providers. As part of the application process, the Social Security Administration considers your input along with information provided from your healthcare, family members, friends, work colleagues, and your employer, who can supply first-hand knowledge of the impairments that qualify you as disabled under the law. Before applying, you and your healthcare providers must understand the specific criteria established under Social Security Administration regulations. Claims are often denied because applicants and healthcare providers do not provide the correct information in the correct format. This guideline is meant to help people with SS, and their healthcare providers work together to submit a successful disability application.

You should begin with a frank conversation with your healthcare provider and family about your future and plan. Should your disability progress to a severely impaired stage, a "what if" plan should be in place well before deciding to begin the application process is made. If your healthcare provider anticipates that SS symptoms are likely to make it impossible for you to remain in the workforce, documenting is the right time. By tracking your worsening symptoms and recording their impact on increasing work-related challenges, your healthcare provider will be able to enter these events into your medical record. It also helps your healthcare provider recommend the appropriate testing and evaluations your disability application will need to supply. These evaluations might consist of a neuropsychological assessment to document changes in cognition or critical thinking that may be interfering with work performance or, if you are over 50, a hearing assessment. Hearing loss alone in those under 50 is not considered a qualifying disability. Persons under 50 are determined to be young enough to learn alternative communication skills. All of this early documentation provides consistent evidence required to support a successful disability application.

**This guideline is intended to make your application process easier. It contains the following:**

- We will explain the role you will play in the application process, and your healthcare provider fills.
- The steps involved in the application process
- The disability criteria for SS, including reference numbers
- Worksheets to help you assemble your medical and work histories, track your symptoms' impact on your work-related activities and log input from family, friends, supervisors, or employers.
- A Disability Evaluation Checklist helps your healthcare providers record the correct medical information and write an effective Medical Source Statement (MSS) in support of your application.
- Sample descriptions used in Medical Source Statements (MSS) from a physician, physician assistant, licensed optometrist, and a psychologist to accompany your medical record in support of your application
- Resources for assistance with the completion of your application
- Information about steps to take if your application is denied
- Additional resources

## Getting Started Planning

Social Security Disability Insurance (SSDI) is a monthly cash benefit payment available to persons who have a good work history and paid enough social security tax into the system to be qualified as insured against disability. Once you are determined to have attained insured status, your disability claim will only be approved if the SSA determines:

- You suffer from a disease, disorder, or injury that is severe enough to prevent you from working an Eight hour work day for five days a week.
- Your severe disability has lasted or is expected to last more than 12 months or result in death.

### SUBSTANTIAL GAINFUL ACTIVITY (SGA)

This is the very first criteria the SSA reviews on all applications. No matter how disabled you are, how many doctors agree, no matter if you have terminal cancer- IF YOU ARE STILL WORKING MORE THAN A BARE MINIMUM WHEN YOU APPLY, YOU WILL BE DENIED. End of story and no excuses. They do not want to hear how you plan to stop working full-time once you are approved. Social Security uses an SGA payment level to determine what is too much work. In 2021, SGA is defined as earning \$1,310 or more a month from working or \$2,190 for a person who is legally blind. The SSA does not consider income from non-employment resources such as interest, investments, pensions, or private disability payments as gainful activity.

If you are currently employed full-time but have entered the planning stage for your disability application, now is the time to discuss with your employer. As your symptoms progress, they may be agreeable to reducing your work-load and hours. This provides you with some income while showing you tried to work as long as you could before being forced to stop. Your employer will be able to give you a letter to send with your application stating your duties and hours were adjusted for your health issues as much as they were able.

## USEFUL TOOLS

### **The SSA Disability Planner ([ssa.gov/planners/disability](https://ssa.gov/planners/disability))**

It is a tool to explain which benefits are available to you, how to apply, and how to qualify. It also outlines what happens once you are approved or denied.

### **The SSA Benefit Eligibility Screening Tool ([ssabest.benefits.gov](https://ssabest.benefits.gov))**

A tool to determine which programs you may qualify for based on a series of questions.

## Healthcare Provider Planning

You may have discussed with your healthcare provider several years earlier about your progression. Most SS patients are still in reasonably good shape when they begin medical care. It helps with your *what-if plan* to have a conversation early on about honesty concerning your progression. When your provider begins to express doubts about your continued ability to maintain full-time employment, it may be time to begin the disability conversation in earnest. The better you and your physician understand the application process, the greater chance of early success.

The SSA requires detailed medical records from every *Treating Source*. Acceptable treatment sources are:

- Licensed physicians
- Licensed or Certified Psychologists
- Licensed Optometrists
- Licensed or Qualified Speech-language Pathologists
- Physician Assistants
- Advance Practice Registered Nurse

Registered nurses, licensed vocational nurses, chiropractors, therapists, clinical social workers may add a written support statement, but these statements will not be considered medical

records from treating sources. The provider who has overseen your case the longest and one who submits the most detailed information will be in the best position to provide your application with supporting solid medical evidence.

## Information Gathering

It now time for you to begin collecting your evidence. Creating a digital file is a suitable method for converting hard copies into a format you will upload if you choose to file your application online. Be sure to make a hard copy file too. You need to keep your worksheets and letters from your family, friends, and employer in one place.

In the Appendix, you will find **Worksheets to Assist You with Your SSD Application**

These four worksheets are designed to help you organize your information you will need to share with your healthcare providers and your SSA interview. Share copies of these worksheets with others as needed but always keep the originals for yourself.

Worksheet One: Applicant Medical History

This worksheet will help you gather the medical information you need to complete your SSDI application.

Worksheet Two: How SS Impacts Your Functioning and Ability to Work

This worksheet will help you describe your SS symptoms and how they impact your functioning on the job.

Worksheet Three: Applicant Work History

This worksheet will help you gather the work, personal, and income history you need to complete your SSDI application.

Worksheet Four: Supporting Information from Family, Friends, Colleagues

This worksheet will help you gather helpful information from people who know you about how your SS or other conditions have impacted your ability to function.

## Healthcare Provider Evidence

Your physicians' role is to provide adequate medical evidence to SSA to support your application. It is not enough for a provider to state you are disabled or believe you meet the listing criteria.

A provider must:

- Provide copies of all related records and include a detailed report with clinical findings supporting your diagnosis and the impact of your SS symptoms on your inability to continue working.
- Your medical records and all supporting information must show that your limitations have already lasted or are expected to last for a continuous period of at least 12 months. This does not mean that your symptoms cannot be better on some days than on others or that your ability to function at work cannot vary from day-to-day. It means your symptoms are progressive, are permanent, and prevent you from continued full-time employment.
- Provide a Medical Source Statement (MSS) outlining their medical opinion concerning any limitations your symptoms impose on your ability to work or perform major life activities. The statement should refer to each specific criteria in the SSA listing (with an assigned number) with a description of the corresponding limitation, the effect on your daily activities, and how it impacts your ability to do work eight hours a day, five days a week. If SSA cannot get enough information from your healthcare provider(s) MSS statements, it might require you to undergo an additional physical or mental exam, known as consultative examinations (CE).
- Describe your current medical history, including SS, other severe health conditions, and your symptoms (including depression, anxiety, cognitive difficulties, side effects of medications) that prevent you from working.

## Updates To Qualifying Neurological Impairments

The Social Security Administration (SSA) finished a significant revision to the criteria for neurological disorder evaluations. These changes came from feedback and administration experiences over the past decade to provide a greater understanding of how the SSA evaluates neurological disorders.

Your key to a successful disability application is by linking your diagnosis, your symptoms, and specific associated challenges with keywords found in the numbered sections of the SSA regulations. Before an actual live decision-maker ever sees your application, it will first be run through a computer algorithm upon the SSA's electronic receipt. This algorithm is designed to identify keywords found in applications that flag Compassionate Allowance Conditions (CAL) as extremely serious and time-sensitive.

This flag will send your application into the electronic system Quick Disability Determination (QDD), which screens applications for disability benefits or SSI filed online. QDD also scans for keywords and phrases that indicate a claim is highly likely to be approved, and it checks that the application **includes all required documentation**. These cases are marked for fast-tracking determination. Applications that are not filed electronically may also be reviewed by claims examiners, who can then flag them for fast-track status. Fast-track status means your application must receive a decision within 30 days.

- Include the exact number listed with each problem
- Word your description with the exact descriptive terms used in each listing.

The SSA decision-makers are not medical professionals. The easier you and your healthcare provider(s) make it for the reviewer to connect your particular symptom or impairment with a specific SSA regulation section, the easier it becomes for your reviewer to approve the application.

## Submit Your Application

- Online
- Over the Phone
- In-Person

Submitting your application online takes the most effort, but it has significant advantages. You control the information and, more importantly, the exact wording entered in your application rather than have an SSA claims representative interpret what you say in an interview and enter your information in their own words. You can take your time filling out the forms, saving information, take a break, and return when you are ready. CAL designations for online applications are entirely automated. Your SSA-3368 (Disability Report—Adult) must be filled out correctly to reflect this is a CAL listed disorder, and you must upload a signed SSA-827 (Authorization to Disclose Information to the Social Security Administration (SSA)).

If you choose to apply in-person or on the phone, call the SSA first to schedule an appointment. This will help reduce your wait at your local SSA field office. There may be a significant wait time to get an appointment. One advantage to an in-person interview is getting to know the person who will submit your application. However, be sure to write out notes to help you share all the details of your circumstances. Remember that any invisible symptoms you have will not be apparent to an SSA claims representative during an in-person meeting, so you will need to describe them fully. If your physician has prescribed any assistive devices, be sure to use them at the meeting.

## Prepare For A Successful Interview

- Make copies of everything you will submit to SSA and order them in your folder. Remember to keep your originals and only submit copies.
- Write down the main points you want to share at the beginning of your interview. Keep these points brief (try not to ramble). Main points should include:
  - I have a (or several) severe disabilities due to superficial siderosis
  - Due to these disabilities, I am unable to work
  - Superficial siderosis is a neurodegenerative disorder listed on the Compassionate Allowance List
  - My severe disability is covered in Sections A and Z of the summary of the SSA Listing of Impairments (referring to the specific section titles and numbers listed)
  - May I have your direct number and extension information (SSA representative) to follow-up on my case later

You will need to bring:

- Birth certificate or other proof of birth; Original
- Proof of US citizenship or lawful alien status if you were not born in the United States;
- US military discharge paper(s) if you had military service before 1968;
- W-2 forms(s) and/or self-employment tax returns for last year;
- Last employer contact information
  - Last work schedule including daily and weekly hours
  - Testimonials from work colleagues, supervisors, or employer
  - If you worked until your medical conditions caused frequent absences or poor performance, provide documentation
  - If you were fired, needed extra help at work, were asked to leave or were encouraged by your employer to apply for disability benefits, provide documentation

- If you have had inadequate job evaluations because of problems with thinking or memory or any other issue related to your SS symptoms, enclose copies of those evaluations with your application
- A completed SSA-3368 (Disability Report—Adult)
- Notes for use during your interview, including a medical and work timeline
- Medical evidence in your possession
  - Treatments and dates
  - All related medical tests and scans with dates and findings (reports)
  - Current prescriptions and dosing schedule
  - Copies of all medical records
  - Copies of your healthcare providers MSS statements (They retain the originals)
  - Current contact information of all healthcare providers
  - Family and friends testimonials

## During Your Interview

Now is the time for you to fully explain your circumstances. Use your notes and timelines to lay out your story in the order events happened. Carefully describe your physical or mental disabilities during your interview. Talk specifically about any problems you have with mobility, balance, fine motor skills, fatigue, vision, bladder function, speech, hearing, mood, thinking, and memory. It is helpful to use words like occasional, frequent, always, intermittent, nightly, daily, mild, severe to express the scope of your symptoms. Give details describing how your physical or mental SS symptoms or other conditions prevent you from working an eight-hour day, five days a week.

Make sure your SSA representative understands superficial siderosis is on the Compassionate Allowance List before they finish inputting your application. When transferring a case into the Electronic Disability Collect System (EDCS), selection software should automatically determine

whether the case qualifies for Compassionate Allowances (CAL) fast-track processing; and the Predictive Model (PM) identifies cases for Quick Disability Determinations (QDD) fast-track processing. When the field office (FO) selects a case, an onscreen message prompts them to complete full non-medical development. **The FO must select OK to close the message box to proceed with the transfer.**

The CAL initiative is designed to quickly identify diseases and other medical conditions that invariably qualify under the Listing of Impairments based on minimal but sufficient, objective medical information. All CAL identified conditions should be entered into a Predictive Model (PM) and are selected for CAL processing based solely on the claimant's claims listed on the SSA-3368 (Disability Report—Adult). CAL cases receive expedited processing within the context of the existing disability determination process.

- The PM identifies most CAL cases upon Electronic Disability Collect System (EDCS) transfer to your States Disability Determination Services (DDS) at the initial claim adjudicative level.
- CAL cases are processed in the DDS by adjudicators who meet the training qualifications outlined in DI 23022.020
- Expedited processing applies to all CAL-identified cases.
- Cases determined to be CAL will also meet the criteria for Quick Disability Determinations (QDD) and designated both QDD and CAL. For example, the case could meet the scoring criteria (all required documentation submitted with application) for QDD and allege a CAL condition.

Even though superficial siderosis is on the CAL list, **your impairment from symptoms must still meet the required degree of disability**, or you may receive a denial. If a CAL case is denied, it retains priority status at all adjudication levels, but a superficial siderosis diagnosis does not guarantee automatic approval.

When your interview is over, and the SSA representative has filed your application. Ask for a copy of your submitted application along with a printout of your yearly wage history.

## After Your Application

Keep records of all communication between the SSA and yourself. Answer all inquiries as soon as possible. If they request additional information, you need to provide this information as quickly as possible. If missing information delays a determination longer than 30 days, your case may lose its QDD status.

Suppose the adjudicator feels your medical records or the Medical Source Statement(s) (MSS) provided by your healthcare provider(s) are not sufficient to determine whether you meet the required degree of disability. In that case, you might receive a notice asking for at least one additional consultative examination (CE). You have the right to call your case examiner and find out why they feel there is insufficient information.

## When You Are Approved

You will receive a notice of approval by mail. This letter will state when you can expect to begin receiving benefits. Be aware there is a mandatory five-month waiting period before your benefits will begin on the designated day of the sixth month. You are also entitled to Medicare. However, your Medicare coverage will not begin until two years after your SSDI benefits begin (a full 29 months after you stop working). To learn more about Medicare coverage for people living with disabilities, go to [socialsecurity.gov/pubs/10043.html](https://www.socialsecurity.gov/pubs/10043.html).

## If You Are Denied

Professionals (paid or unpaid) are called SSDI claimant representatives. Representatives are usually disability attorneys, but they do not always have to be. You can find a representative by:

- Contacting the National Organization for Social Security Claimants Representatives at [nosscr.org](http://nosscr.org) or by calling 1-800-431-2804
- Your local SSA field office will also have a list of representatives. Be sure to ask for a complete written explanation of fees and rates before agreeing to meetings or signing any documents.

For more information about representatives and fees:

visit: [ssa.gov/pubs/EN-05-10075.pdf](http://ssa.gov/pubs/EN-05-10075.pdf) or [ssa.gov/planners/thirdparty.html](http://ssa.gov/planners/thirdparty.html)

You have the right to appeal if your application is denied or not satisfied with the determination. Keep all notices mailed to you by SSA and Disability Determination Services (DDS). You will only have 60 days after you receive the notice of SSA's decision to appeal. Remember, your CAL application ensures your appeal has priority status, so take care not to let it lapse by inaction.

## If You Need Assistance Filing Your Application

There are several ways a friend, family member, or other representatives can help you apply for and manage your disability benefits. They can assist with part of the application process, such as gathering and organizing all the necessary work and medical records into a folder or keeping a journal. They can accompany you on visits to your doctor(s) and SSA, sit beside you, and help answer any tough questions. They also can help fill out the worksheets in this guideline.

If you cannot manage any part of the application process yourself, or if you want or need someone to act on your behalf or in your absence with SSA, you can appoint an Authorized

Representative. An attorney, non-attorney representative, specializing in Social Security, friend, or family member can serve as your Authorized Representative. That person will need to develop a telephone relationship with your healthcare provider(s) and become familiar with all the documentation required to submit a successful application. Both you and the person representing you must complete and sign Form SSA-1696 (Appointment of Representative). You can download and complete this form at [socialsecurity.gov/representation](https://www.socialsecurity.gov/representation).

If you want a representative but do not know how to find one, ask your local SSA field office. Some representatives charge fees. Others do not. To understand how representatives can charge fees and how SSA approves fees, refer to [ssa.gov/pubs/EN-05-10075.pdf](https://www.ssa.gov/pubs/EN-05-10075.pdf).

Note: SSA does not recognize power of attorney.

# SSA LISTING FOR EVALUATION

## SUPERFICIAL SIDEROSIS DISABILITY EVALUATION UNDER SOCIAL SECURITY

### PRIMARY

Meets 11.17 under 11.00 NEUROLOGICAL – ADULT

11.17 Neurodegenerative disorders of the central nervous system (List: Superficial Siderosis of the Central Nervous System) characterized by A or B:

A. Disorganization of motor function in two extremities (see 11.00D1), resulting in an extreme limitation (see 11.00D2) in the ability to stand up from a seated position, balance while standing or walking, or use the upper extremities.

OR

B. Marked limitation (see 11.00G2) in physical functioning (see 11.00G3a), and in one of the following: Understanding, remembering, or applying information (see 11.00G3b(i)); or Interacting with others (see 11.00G3b(ii)); or Concentrating, persisting, or maintaining pace (see 11.00G3b(iii)); or Adapting or managing oneself (see 11.00G3b(iv)).

NOTE: Adjudicators may, at their discretion, use the Medical Evidence of Record or the listings suggested to evaluate the claim. However, the decision to allow or deny the claim rests with the adjudicator.

## SECONDARY

### MEETS 2.00 – SPECIAL SENSES AND SPEECH, ADULT

Which includes the abnormalities of the eye, optic nerve, or optic tracts that can occur in SS

### MEETS 12.00 – MENTAL DISORDERS

Which includes mood and cognitive disorders that can occur in SS as well as in other medical or psychiatric conditions

By now, you should realize how important documenting each symptom, progression timeline, and negative work-experience impact is to make a successful application. Each of these sections of SSA regulations has numerous subsections with precise criteria. If you have been diagnosed with SS and you do not meet the standards for disability under one specific section, you may still qualify under one of the other two sections. Remember, you only have to meet the criteria of one section. Refer to Appendix-SS for a detailed summary of the superficial siderosis code sections.

# SSA CAL SUPERFICIAL SIDEROSIS LISTING

## Compassionate Allowance Information from the Social Security Administration Handbook

DI 23022.337 Superficial Siderosis of the Central Nervous System

### SSA SUGGESTED PROGRAMMATIC ASSESSMENT\*

#### Suggested MER for Evaluation

- A. Clinical history and examination that describes the diagnostic features of the impairment;
- B. Results of MRI/CT scan of the brain surface, spinal cord, or cranial nerves.

### SSA APPROVED ICD-9-CM/ICD-10-CM CODING

ICD-9: 331.0

ICD-10: J63.4

### PROGRESSION

Superficial Siderosis of the CNS progresses slowly over decades. This disease affects people of a wide range of ages, with men being diagnosed approximately three times more frequently than women. The number of reported superficial siderosis cases has increased with advances in MRI technology, but it remains a rare disease.

### TREATMENT

Treatment varies based on the underlying cause and severity of the condition and may include surgery and medications. If identified early in the diagnosis, ablating or plugging the bleeding source may help restrict further complications. The bleeds may be attributed to complications in the spine, such as tumors or other similar problems.

Some other medication forms, such as iron chelators, have been tried but have not proven beneficial.

Some individuals may be at risk of developing dementia and are treated with folic acid in tablet form, vitamin B<sub>12</sub> in daily tablet form, or a monthly injection.

To lessen the chance of a return of TIA's or strokes, various forms of medication are prescribed, such as blood thinners and the traditional half of an aspirin a day.

For those experiencing permanent headaches, anti-depressants in mild doses are found to provide long-term relief, along with common medication such as Panadol.

## ALTERNATE NAMES

Superficial Siderosis of the CNS; Superficial Hemosiderosis of the CNS; Superficial Hemosiderosis of the Central Nervous System

## DESCRIPTION

Superficial Siderosis of the Central Nervous System (CNS) is a progressive disease of the central nervous system caused by the accumulation of hemosiderin (iron salt) deposits on the brain surface, spinal cord, or cranial nerves.

The hard iron salt deposits are created from chronic bleeding into the subarachnoid space or brain surface underneath the three protective membranes. In most cases, the bleeding source is never located due to a considerable time delay before diagnosis. More than one bleed is required to cause superficial siderosis.

## DIAGNOSTIC TESTING AND PHYSICAL FINDINGS

Diagnostic testing: An MRI of the head, spinal cord, or cranial nerves is needed to diagnose this disease. CT myelogram may assist with identifying leakage from a Dural defect.

Physical findings: Individuals with Superficial Siderosis of the CNS may have difficulty with:

- Hearing;
- Ability to smell and taste;
- Balance;
- Coordination and weakness of limbs;
- Difficulty with bladder and bowel functions;

- Eye movements;
- Early dementia;
- Bilateral sciatica;
- Pain in lower back and joints

Other less common side effects include:

- Transient ischemic accidents (TIA) or mini-strokes;
- Orthostatic headache;
- Cognitive difficulties;
- Loss of ability to hold one's head up;
- Compression of gullet muscles.

## APPENDIX-SS

### SUMMARY OF SUPERFICIAL SIDEROSIS RELATED SSA LISTING OF IMPAIRMENTS

#### **MAIN SSA LISTING: 11.17 NEURODEGENERATIVE DISORDERS OF THE CENTRAL NERVOUS SYSTEM (OFFICIAL DISORDER: SUPERFICIAL SIDEROSIS OF THE CENTRAL NERVOUS SYSTEM)**

- A) When determining a person's ability to stand up, balance, walk or perform fine and gross motor movements (11.00D), SSA evaluates signs and symptoms such as flaccidity, spasticity, spasms, incoordination, imbalance, tremor, physical fatigue, muscle weakness, dizziness, tingling, and numbness.
- B) When determining whether a person with SS has limitations of physical and mental functioning (11.00G), SSA evaluates impairments or signs and symptoms that develop as a result of SS, such as fatigue, visual loss (which may be evaluated under 2.0), pain, trouble sleeping, impaired attention, concentration, memory or judgment, mood swings, and depression. Physical functioning may also include functions of the body that support motor abilities, such as breathing and swallowing. Note regarding Fatigue: SSA recognizes that fatigue is "one of the most common and limiting symptoms of neurological disorders. This fatigue can be physical (lack of muscle strength) or mental (decreased awareness or attention). When SSA evaluates a person's fatigue, they consider the intensity, persistence, and effects of fatigue on their functioning. Specifically, SSA wants a description of fatigue characteristics of SS and a detailed description of how fatigue impacts the person's physical or mental functioning.
- C) Note regarding Visual Impairment: if a person has a visual impairment that SS causes, the visual impairment may be evaluated under Special Senses and Speech - Adult (2.0). The visual disorders covered in this section of regulations include the abnormalities of the eye, optic nerve, or optic tracts that can occur in SS, resulting in loss of visual acuity (2.02), reduction of the visual field (2.03), or loss of visual efficiency (2.04).

- D) Suppose a person with SS does not satisfy the requirements outlined in 11.17. In that case, she or he can also be considered for cognitive impairment under 12.02 (neurocognitive impairments that result from neurological disorders) or depressive, bipolar, and related disorders (12.04), or anxiety and obsessive-compulsive disorders (12.06) resulting from her or his SS. Therefore, a person with significant cognitive impairment or mood disturbance but mild or no physical impairments may qualify for SSD under 12.00.
- E) 12.02 Neurocognitive Disorders — includes disorders characterized by a clinically significant decline in cognitive functioning. Symptoms and signs may include but are not limited to: disturbances in memory, executive functioning (e.g., regulating attention, planning, inhibiting responses, decision-making), visual-spatial functioning, language and speech, perception, insight, judgment, and insensitivity social standards.
- F) a. Medical criteria must be present in the medical evidence — all relevant medical evidence from the person's physician, psychologist, and other medical sources such as physician assistant, psychiatric nurse practitioners, licensed clinical social workers, and clinical mental health counselors. Evidence may include: reported symptoms; medical, psychiatric, and psychological history; results of physical or mental status exams, structured clinical interviews, psychiatric or psychological rating scales, measures of adaptive functioning, or other clinical findings; psychological testing, imaging results, or other laboratory findings; the diagnosis; the type, dosage and beneficial effects of medications that are being taken; the type, frequency, duration and beneficial effects of therapy that is being received; side effects of treatment that may impact function; observations of the person' functioning during examinations or therapy; Information about sensory, motor or speech abnormalities or about the cultural background that may affect the evaluation of the mental disorder; the expected duration of the symptoms and signs of the disorder
- G) For 12.02 Neurocognitive Disorder, the medical documentation must show a significant decline from a prior level of function in one or more the following areas: complex

attention, executive function, learning, and memory, language, perceptual-motor skills or social cognition AND Extreme limitation of one OR marked limitation of two of the following areas of functioning: understanding, remembering or applying information, interacting with others, concentrating, persisting or maintaining pace OR Medically-documented history of a severe and persistent disorder over at least two years, which is being treated with at least some benefit, but still leaves the person with minimal capacity to function in the work setting.

SSA also considers that a person may be able to perform a function some times and not others. The limitation in a person's functioning must last or be expected to last at least 12 months.

## APPENDIX-PS

### MEDICAL SOURCE STATEMENT (MSS) EXAMPLES

#### **SAMPLE ONE**

My patient, Ms. X, has Disorganization of motor function in both legs (11.00D1), which has resulted in an extreme limitation (11.00D2) in her ability to stand up from a seated position without assistance and balance safely while standing, requiring her to use a wheeled walker for mobility. Her lower limbs are weak and spastic [scores], with significant foot drop on the right side, for which she wears an orthotic to reduce the risk of falls. As a result, Ms. X cannot navigate safely to and from her place of work and is unable to carry out her work activities for more than 1 hour before becoming too fatigued to continue. As is common in SS, Ms. X's fatigue, both physical and mental, comes on suddenly and is all-consuming, requiring a one-to-two-hour period of rest or sleep before she can resume any physical or mental activity.

#### **SAMPLE TWO**

My patient, Mr. Y, has Disorganization of motor function (11.00D1), resulting in a marked limitation (11.00G2) in physical functioning caused by incoordination, impaired balance, and significant intention tremor in his right hand/arm. He has significantly decreased visual acuity (2.02) due to optic neuritis and a reduction in the visual field (2.03) [scores]. Because of these impairments, Mr. Y cannot travel safely to and from work, maneuver safely within the workplace, carry out the job's manual functions on a sustained basis or see adequately to complete tasks. Mr. Y has also experienced a marked decline in cognitive functioning (12.02) [test scores showing decline], principally in the areas of information processing speed, memory, and perceptual-motor skills. Because of these deficits, Mr. Y has extreme difficulty remembering and applying the information he has heard, keeping up with conversations in the workplace, and completing his tasks in a timely way.

### **SAMPLE THREE**

My patient, Ms. Z, has a moderate gait impairment resulting from spasticity and weakness (11.00G2) [scores] and bladder symptoms of urgency and frequency that she manages with partial success with anticholinergic medication. However, these symptoms make it difficult for her to navigate to and from the bathroom quickly and safely. Ms. Z's cognitive function (12.02) has decreased markedly over the past two years [scores]. She has lost essential executive functions and is no longer able to organize her work activities, plan and prioritize her tasks, make sound decisions or use good judgment in her work activities and interpersonal interactions.

### **SSA EVALUATION TERMS**

**Disorganization of function:** The neurologic condition interferes with the movement in at least two extremities

**Extreme limitation:** Inability, without assistance from another person or an assistive device, to stand from a seated position, maintain and complete work-related activities involving fine motor movements and gross motor movements.

**Marked limitation:** To satisfy the requirements, the person's SS must result in a significant limitation in physical functioning and a significant limitation in one of the four areas of mental functioning.

**Physical functioning:** The person is seriously limited in independently initiating, sustaining, and completing work-related activities because of persistent and intermittent physical symptoms.

**Mental functioning:** the person is seriously limited in the ability to function independently, appropriately, effectively, and on an ongoing basis in work settings because of mood and or cognitive symptoms.

## DISABILITY EVALUATION CHECKLIST FOR PROVIDERS

This checklist will assist you to:

- Plan a practical disability application with your patient
- Outline the key points to be covered in the **Medical Source Statement (MSS)** that SSA requires you to submit along with the medical/psychological evidence in support of your patients' application.

The numbers in parentheses refer to specific sections in the SSA criteria for evaluating disability. Comprehensive evidence from you will increase your patient's chances of receiving benefits, so use this checklist to ensure complete documentation of all medical/psychological evidence about your patient's condition(s), and reference of the relevant sections of the **SSA Listing Regulation**.

As described in Appendix-SS of the Guideline, the common physical, cognitive and emotional symptoms of SS that can interfere with an adult's ability to function at work or in school are covered in three separate sections of the Listing:

### **11.00— NEUROLOGICAL – ADULT**

The SSA evaluates neurological disorders such as superficial siderosis that may manifest in a combination of limitations in physical and mental functioning.

#### **11.17 — NEURODEGENERATIVE DISORDERS OF THE CENTRAL NERVOUS SYSTEM (OFFICIAL DISORDER: SUPERFICIAL SIDEROSIS OF THE CENTRAL NERVOUS SYSTEM)**

A. Disorganization of motor function in two extremities (see 11.00D1), resulting in an extreme limitation (see 11.00D2) in the ability to stand up from a seated position, balance while standing or walking, or use the upper extremities.

OR

B. Marked limitation (see 11.00G2) in physical functioning (see 11.00G3a), and in one of the following:

Understanding, remembering, or applying information (see 11.00G3b(i)); or

Interacting with others (see 11.00G3b(ii)); or

Concentrating, persisting, or maintaining pace (see 11.00G3b(iii)); or

Adapting or managing oneself (see 11.00G3b(iv)).

**2.00 — SPECIAL SENSES AND SPEECH**, which includes the abnormalities of the eye, optic nerve, or optic tracts that can occur in ss.

**12.00 — Mental Disorders**, which includes mood and cognitive disorders that can occur in SS as well as in other medical or psychiatric conditions. If a person with SS does not meet the criteria for disability due to physical impairments, it is still possible to qualify for disability due to cognitive or mood problems under 12.00. Even if you believe that your patient meets the criteria for disability under 11.00 based solely on impairments in physical functioning, it is recommended that you include information in this evaluation.

PROVIDER EVALUATION WORKSHEET: NEUROLOGICAL

**CHECK ALL SYMPTOMS THAT INTERFERE WITH YOUR PATIENT'S  
PHYSICAL FUNCTIONING:**

- Flaccidity  Spasticity  Spasms
- Incoordination  Imbalance  Tremor
- Physical fatigue  Weakness  Dizziness
- Numbness/tingling  Respiratory function  Swallowing
- Vision [may also be evaluated under 2.0 of the listing]

**Neurologic exam:**

**Date(s):** \_\_\_\_\_

**Relevant findings:** \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

**Tests conducted if any:**

**Date(s):** \_\_\_\_\_

**Relevant findings:** \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

OR

**B. Marked limitation (11.00G2) in physical functioning AND in at  
least one area of mental functioning:**

**CHECK ALL SYMPTOMS THAT APPLY:**

- Flaccidity  Spasticity  Spasms
- Incoordination  Imbalance  Tremor
- Physical fatigue  Weakness  Dizziness
- Numbness/tingling  Respiratory function  Swallowing
- Vision [may also be evaluated under 2.0 of the listing]

**Neurologic exam:**

**Date(s):** \_\_\_\_\_

**Relevant findings:** \_\_\_\_\_

\_\_\_\_\_

**Additional tests, if any:**

**Date(s):** \_\_\_\_\_

**Relevant findings:** \_\_\_\_\_

\_\_\_\_\_

**AND**

CHECK AT LEAST ONE OF THE FOLLOWING FOUR AREAS OF MENTAL FUNCTIONING THAT SERIOUSLY LIMITS YOUR PATIENT'S ABILITY TO PERFORM INDEPENDENTLY, APPROPRIATELY, EFFECTIVELY AND ON A SUSTAINED BASIS IN WORK SETTINGS.

A person may have a marked limitation when several activities or functions are impaired or when only one is impaired. The a person does not have to be unable to perform an activity

as long as the degree of limitation seriously limits her or his ability to function.

**☐ 1. Understanding, remembering, or applying information (11.00G3b(1))**

**Evaluation(s)**

**Date(s):** \_\_\_\_\_

**Relevant findings:** \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

**Specific tests done, if any:**

**Date(s):** \_\_\_\_\_

**Relevant findings:** \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

**OR**

**☐ 2. Interacting [appropriately, effectively, and comfortably] with others (11.00G3b(ii))**

**Evaluation(s)**

**Date(s):** \_\_\_\_\_

**Relevant findings:** \_\_\_\_\_

\_\_\_\_\_

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**Specific tests done, if any:**

**Date(s):** \_\_\_\_\_

**Relevant findings:** \_\_\_\_\_

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**OR**

**3. Concentrating, persisting or maintaining pace**

(see 11.00G3b(iii))

**Evaluation(s)**

**Date(s):** \_\_\_\_\_

**Relevant findings:** \_\_\_\_\_

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**Specific tests done, if any:**

**Date(s):** \_\_\_\_\_

**Relevant findings:** \_\_\_\_\_

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**OR**

**□ 4. Adapting or managing oneself [appropriately, effectively, comfortably] (11.00G3b(iv))**

**Evaluation(s)**

**Date(s):** \_\_\_\_\_

**Relevant findings:** \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

**Additional tests, if any:**

**Date(s):** \_\_\_\_\_

**Relevant findings:** \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

# APPENDIX-WS

## WORKSHEETS FOR PERSONAL RECORD GATHERING

### **1. MEDICAL HISTORY**

The purpose of this worksheet is to help you gather all the medical information related to your disability that you will need for your application. Collect as much of the following information as possible and fill out each section below. You can refer to the SSA Listing of Impairments to help organize your information by each listing criteria that apply to you. Use additional sheets of paper if needed. Bring a copy of this worksheet to the appointments with your healthcare provider(s) to discuss the information you need for your application and double-check for any missing information. Bring a copy of this worksheet to your SSA interview, along with copies of any relevant information you have gathered. Keep all of your originals.

### **2. HOW SS SYMPTOMS IMPACT YOUR FUNCTIONING AND ABILITY TO WORK**

The purpose of this worksheet is to help you describe how your SS symptoms or other conditions affect your ability to work. The worksheet is organized around the main sections of the SSA Listing that relate to SS impairments. In each area, be sure to describe how your symptoms have changed your ability to work. Think about activities you did at work before your disability and what activities you can no longer do. Think about activities that are too complex, tiring, or painful to perform for very long or at all, as well as activities that you cannot complete without assistance. The examples below are designed to help you think about your situation. Be thorough. If you do not have room to write in the space provided, use additional paper. Use the information you include here to talk with your healthcare provider(s) and SSA representative. Give your healthcare provider(s) a copy of this sheet so that he or she can use this information when writing your Medical Source Statement (MSS). KEEP YOUR ORIGINALS

### **3. WORK HISTORY**

The purpose of this worksheet is to help you gather all of the personal, income, and work history information you need for your application. Collect all of the documents and information on the list. Include a description of the type of work you performed, the length of time you held that type of job, and hours scheduled per day/week. Attach all separate documents to this worksheet.

### **4. SUPPORTING INFORMATION FROM OTHERS**

SSA is aware that you spend minimal time with your healthcare providers. Depending on how often you are seen, time-of-day, what you are talking about, or doing during your appointment, your providers may not be fully aware of the limitations you experience in your home and work activities. In addition to the information you and your healthcare providers will provide to SSA, Information from those who know you well and see your function daily can be extremely helpful for the person who is evaluating your application. This worksheet provides you with some questions to ask some of these critical people in your life. You can make a copy of the page for each person. Keep the originals for yourself and share copies with your healthcare providers and the SSA.

## WORKSHEET ONE: MEDICAL HISTORY

A. List all illnesses, injuries, or conditions that prevent you from working. This list should include all symptoms, whether or not they are related to SS

B. When did you become unable to work in any substantial gainful activity (SGA) because of your medical condition? (MM/DD/YYYY)

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C. If you are receiving Medicaid, write your Medicaid ID number here: \_\_\_\_\_ and include a copy of your Medicaid benefit card.

D. List the names of your physician(s), rehabilitation therapists (physical therapist, occupational therapist), speech/language pathologist, a mental health professional who has treated you or examined you for your disability-related illnesses, injuries, or conditions in the past. Also add those whom you expect to treat you in the future. You should also include any medical professionals who know about your SS symptoms' effects even if they did not treat or examine you for it.

1. Healthcare providers treating motor or physical symptoms, including fatigue

2. Healthcare providers treating vision symptoms

### 3. Healthcare providers assessing or treating cognitive or mental health problems

E. Hospitals, clinics, rehabilitation facilities, or emergency rooms you visited. For each entry, include name, address, phone, the reason for visit, date of admission, and inpatient treatment discharge.

F. All medications you take and why you take them (for SS and any other conditions you are treating). For each medication, include the name of the medication, dosage (if known), length of prescription, the reason for taking the medication, name of prescribing physician, physician assistant or nurse practitioner, side effects from the medication. Also, list any medications that you have tried in the past and why you stopped taking them.

G. Medical tests you have had or are going to have related to your SS symptoms or other conditions. For each test, include the name of the test, place of test, the reason for the test, name of healthcare provider who ordered the test, test date(s) MM/DD/YYYY, test results.

## WORKSHEET TWO: HOW SS SYMPTOMS IMPACT YOUR FUNCTIONING AND ABILITY TO WORK

### 1. THE IMPACT OF PHYSICAL SYMPTOMS, INCLUDING FATIGUE

Describe how your SS symptoms or other conditions have impacted physical or other work activities. Use these examples to help you describe your circumstances and write your statement.

- Sitting at your workstation or keeping your balance in one place
- Standing, walking outside (including how long it would take you to walk 100 yards — the length of one football field), walking around your workplace, or requiring an assistive device to walk or maintain your balance (including descriptions of tripping or falling and your use of an assistive device such as a cane, walker, motorized scooter or wheelchair)
- Completing a full workday/work-week, including travel to and from work including a description of the amount of rest you need on weekends in order to maintain your work schedule, as well as noting the use of vacation time when you are out of paid sick days)
- When you engage in any activity lasting one hour or longer
- Keeping up with the pace of your coworkers
- Manual activities like using a keyboard, writing, or handling papers
- Difficulty with lifting or carrying; list the weight limit you can safely lift
- Problems with traveling to work either with public transportation or driving
- Speaking, understanding, or being understood by others
- Managing SS related pain, heat/cold sensitivity during scheduled work hours
- Controlling your bowel or bladder
- Dressing and grooming activities

- Completing household chores such as vacuuming, sweeping, or mopping. List how long each activity takes you to complete and if you need to take frequent rest breaks.
- Repeat for outdoor chores such as yard work, outside maintenance

Complete your statement on a separate paper using as many pages as needed.

Describe your physical and motor limitations related to your work and other activities. Be sure to describe any assistance or accommodations you receive at work. Use words like always, sometimes severe, moderate to describe your difficulties and be as detailed as you can.

## 2. THE IMPACT OF VISUAL SYMPTOMS

Describe how your visual symptoms have impacted your work activities. Describe your visual limitations related to your work and other daily activities, making sure to include any compensatory strategies or tools you are using. Use words like always, sometimes, severe, moderate to describe your difficulties and be as detailed as you can. Use these examples to describe your circumstances in your own words.

- Writing
- Reading (Do you require enlarged large font)
- Using electronic or computer screens
- Seeing materials at work-related presentations
- Using or operating work-related equipment
- Driving a vehicle
- Navigating your workday if you experience double vision, nystagmus, or eye pain
- Watching television or a movie

### 3. THE IMPACT OF COGNITIVE SYMPTOMS

How have changes in your thinking, memory, attention, organization, planning, problem-solving, visual-spatial skills impacted your work activities? Use these examples to help describe your problems in your own words, making sure to include any compensatory strategies or tools you are already using. Use descriptive words like always, sometimes, severe, moderate to describe your difficulties and be as detailed as you can.

- Understanding, participating, and keeping up with workplace discussions, either one-on-one or in groups
- Maintaining attention and focus during work activities or conversations without getting distracted
- Planning and prioritizing your work activities. Maintaining organization in your activities, papers/files, supplies at work and home
- Making effective decisions with sound judgment and managing oneself appropriately
- Working with numbers, balancing a checkbook, following a recipe
- Driving to and from work and navigating around the workplace without getting lost
- Working at a task requiring concentration and focus for more than a few minutes without becoming overwhelmingly fatigued
- Remembering assignments and appointments, Information from colleagues, Information from reading materials

Complete your statement on a separate paper using as many pages as needed.

#### 4. THE IMPACT OF DEPRESSION OR OTHER MOOD CHANGES

How have your mood changes affected your work activities and interactions with others at work and home? Use these examples to help you describe your circumstances in your own words.

- Depressive symptoms interfering with attention, focus, ability to complete tasks
- Depressive symptoms interfering with effective interactions with others and your ability to behave appropriately
- Moodiness and irritability impacting interactions with others and the ability to behave appropriately
- Extreme mood swings impacting judgment, decision-making, interactions with others, and ability to behave appropriately
- Uncontrollable episodes of laughing or crying that disrupt work activities and interactions with others
- Severe anxiety interfering with attention, focus, and ability to complete tasks

Complete your statement on a separate paper using as many pages as needed.

## WORKSHEET THREE: WORK HISTORY

### Personal Information:

- Original or certified copy of your birth certificate. If you were not born in the United States, you need proof of US citizenship or legal residency.
- Your checking or savings account number if you have one.
- Social Security Number(s) for yourself, your spouse, and minor children who live in your home.
- Name, address, and phone number of a person whom SSA can contact if they are unable to get in touch with you

### Employment History:

- If you were in the military service — the original or certified copy of military discharge papers (Form DD 214) for all active duty periods.
- If you worked last year — your W-2 form; if you were self-employed, your federal tax return IRS 1040: Schedules C and SE.
- Workers' compensation information (if any), including date of injury, claim number, and proof of payment amounts.
- Job descriptions and dates you worked in the past 15 years

## WORKSHEET FOUR: SUPPORTING INFORMATION FROM OTHERS

Print or make copies of the following page for family members, friends, colleagues, and your last employer to fill out. They will be asked to list how your symptoms negatively impacted the various activities of your daily life or work.

Print

Name: \_\_\_\_\_

Relationship to applicant: \_\_\_\_\_

How long you have known the applicant: \_\_\_\_\_

1. What kinds of changes have you seen in the applicant's ability to function at work or home? Please describe any physical changes related to walking, sitting, balance, coordination, manual dexterity, maintaining energy, stamina, strength, driving, or other functions. Include information about the severity and frequency of the problems, as well as how long they have been occurring:

2. Please describe any vision changes you have direct knowledge of that are impacting reading, writing, driving, completing tasks, or anything else you have noticed. Include information about the severity and frequency of the problems, as well as how long they have been occurring:

3. Please describe any problems with cognitive functioning impacting memory, attention, focus, judgment, planning and prioritizing, problem-solving, decision-making, ability to stay on task and complete tasks, driving without getting lost, or anything else you have noticed. Include information about the severity and frequency of the problems, as well as how long they have been occurring:

4. Describe any mood changes including depression, anxiety, severe irritability, mood swings, uncontrollable episodes of laughing or crying impacting ability to participate fully in activities, complete tasks, interact comfortably and appropriately with others, behave appropriately, or anything else you have noticed. Include information about the severity and frequency of the problems, as well as how long they have been occurring:

5. Please list any other changes you have noticed that does not seem to fit in the above categories:

You may use as many pages as you need to complete this questionnaire.

## SUPERFICIAL SIDEROSIS RESEARCH ALLIANCE MISSION



To seek, raise, and provide funding in support of medical research for the benefit of the rare disease community affected by neurodegenerative disorder superficial siderosis and the identified symptoms of this disease, such as ataxia and hearing loss, and myelopathy.

To fulfill our mission, the SSRA leads the way on advocacy, education, and legislative issues. To drive change, we must help educate on every level-patient, caregiver, and medical professionals. The Superficial Siderosis Research Alliance (SSRA) is proud to be a source of superficial siderosis-related topics.

To learn more about superficial siderosis, visit: [livingwithss.com](http://livingwithss.com)

To learn more about the SSRA Mission, visit: [ssra.livingwithss.com](http://ssra.livingwithss.com)

To enroll in the Superficial Siderosis Patient Registry visit: [superficialsiderosis.org](http://superficialsiderosis.org)

The information provided is based on professional advice, personal SSDI application experience, and opinion, but does not constitute medical or legal advice. For specific medical advice, consult a qualified physician. For specific legal advice, consult a qualified attorney. The SSRA does not endorse products, services or manufacturers and assumes no liability for the recipient's use of any information provided.

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