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# Sickle Cell Disease and the Social Security Disability Evaluation Process for Adults

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## If You Have Sickle Cell Disease

If you have sickle cell disease, you may be eligible for disability benefits through Social Security's Disability Insurance (SSDI) or Supplemental Security Income (SSI) programs. Social Security pays disability benefits to people who can't work because they have a severe medical condition (also called an impairment) that has lasted or is expected to last for a continuous period of at least 1 year or to result in death. The medical rules we use to decide whether you are disabled are the same for SSDI and SSI, but other non-disability requirements are different.

This publication will help adults with sickle cell disease to understand the Social Security disability evaluation process and provide tips for helping with that process.

## What We Mean by Disability

The definition of disability under Social Security is different from other programs. We pay only for total disability. No benefits are payable for partial or short-term disability.

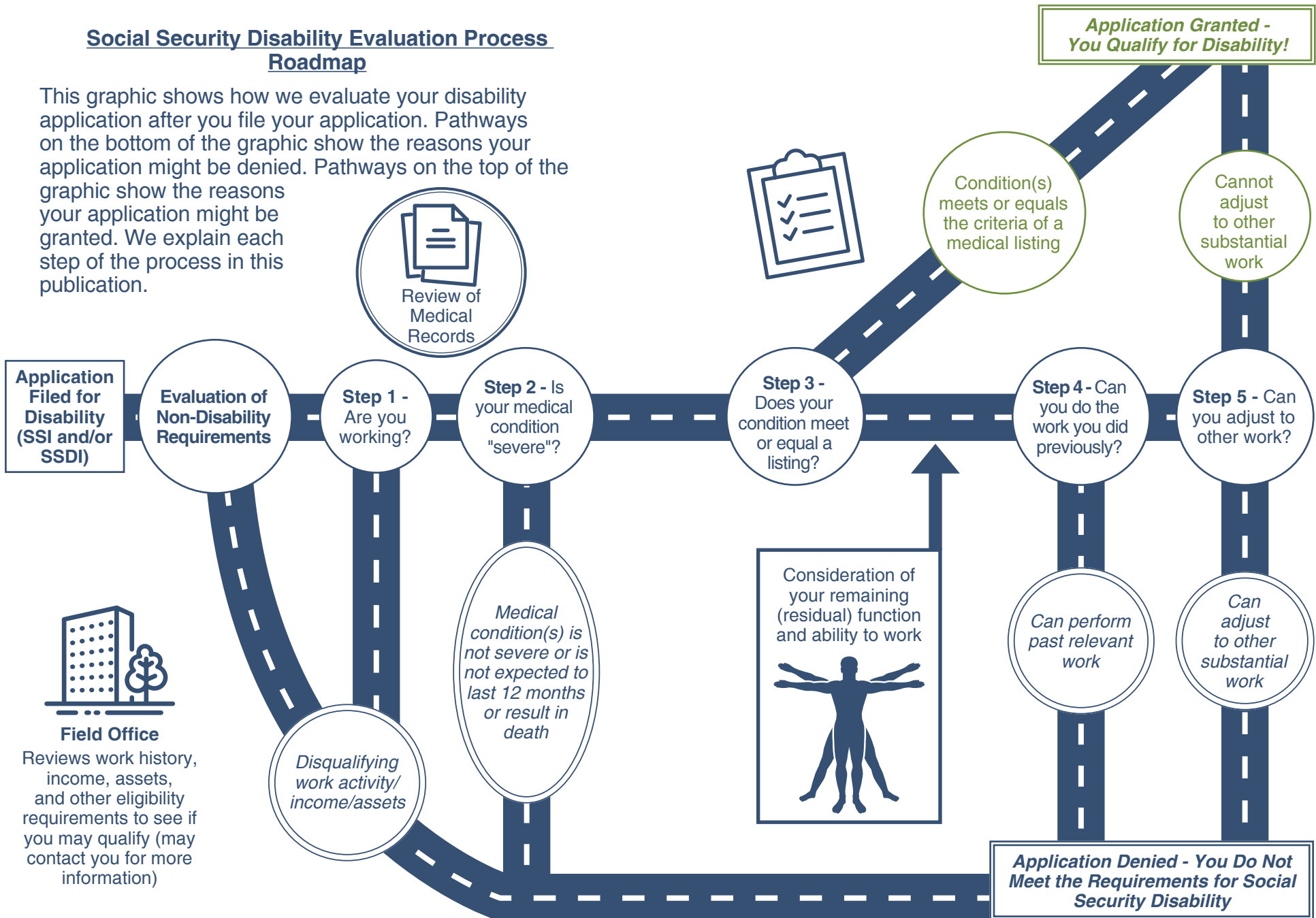
We consider you to have a disability under our rules if *all* the following are true:

- You cannot do work at the substantial gainful activity (SGA) level because of your medical condition.
- Your condition has lasted or is expected to last for a continuous period of at least 1 year or to result in death.
- You cannot do work you did previously or adjust to other work because of your medical condition.

This is a strict definition of disability that Congress created.

## Social Security Disability Evaluation Process Roadmap

This graphic shows how we evaluate your disability application after you file your application. Pathways on the bottom of the graphic show the reasons your application might be denied. Pathways on the top of the graphic show the reasons your application might be granted. We explain each step of the process in this publication.



## Non-Disability Requirements

The field office first checks to see if you meet the non-disability eligibility requirements. These requirements may include age, employment, marital status, citizenship and residency, and Social Security insurance coverage information.

- The SSDI program gives benefits to people who are disabled or blind and who are “insured” by paying into the Social Security trust fund through their payroll taxes. For SSDI eligibility, the field office will check your contributions to the Social Security trust fund (or those of your spouse or parents) to see if you are “insured.”
- The SSI program makes payments to people who have limited income and resources and are age 65 or older, or are blind, or have a disability (including children). For SSI eligibility, the field office checks income, resources, and living arrangement information.
- You might meet the non-disability eligibility requirements for SSDI, SSI, both SSDI and SSI, or neither SSDI nor SSI. If we decide you meet the non-disability requirements for either program, we then look to see if you meet the disability requirements.

## Adult Disability Evaluation Process (5 Steps)

After the field office has confirmed your non-disability eligibility, they will send your case to the State agency for the evaluation of disability. The State agency is called the Disability Determination Services or DDS.

The DDSs are State agencies that are fully funded by the Federal Government. Trained staff at the DDS begin by developing the medical and nonmedical evidence needed to evaluate your claim. They follow a 5-step evaluation process to determine whether you are disabled under the law. Then, the DDS returns the case to the field office for appropriate action.

If the DDS finds that you are disabled, the field office completes any remaining non-disability development, calculates the benefit amount, and begins paying benefits. If the DDS finds that you are not disabled, you will get a letter explaining the decision and your right to appeal it.

Below, we describe the 5-step evaluation process that we use to decide if you are disabled.

### **Step 1: Are you working?**

We generally use earnings guidelines to decide whether your work activity is substantial gainful activity (SGA). If you are working in 2024 and your monthly earnings average more than \$1,550 (\$2,590 if you're blind), your work is generally considered SGA. See the annual *Update* (Publication No. 05-10003) for more information.

- ⊗ **If your work activity is SGA, you cannot be considered to have a disability, and your application will be denied.**
- **If you are not working or are working below the SGA level, we will continue to step 2.**

It is important to note that our definition of disability is significantly different from some other definitions of disability you might be familiar with.

Example: Susie, who is not blind, is working in 2024 and earns \$2,500 per month. Susie does not have any exceptions or deductions from earnings that can be taken under our SGA rules. Since Susie is working and earning SGA, Susie does not qualify for Social Security disability benefits. Susie's application would be denied at "step 1."

Example: Sally is working in 2024 and earns \$1,200 per month. Because these earnings are below the SGA level, Sally is not earning SGA. We would continue to step 2.



## Step 2: Is your medical condition “severe”?

At this step, the DDS will begin reviewing your medical and nonmedical evidence. If the DDS cannot get evidence from your medical sources, or if there is not enough evidence in your medical records to evaluate your case, the DDS will arrange for you to attend a consultative examination at no cost to you. For more information about consultative examinations, see “*A Special Examination Is Needed for your Disability Claim*” (Publication No. 05-10087).

We will look at your medical record to determine what medical conditions you have and whether or not they are severe. We need medically acceptable clinical and laboratory findings to show that you have a particular medical condition.

Under the law, we cannot find you disabled based on symptoms alone, but the effects of symptoms may be an important factor in determining whether you are disabled. If clinical signs or laboratory findings show that you have a medical condition, we refer to it as a “medically determinable impairment” or MDI.

- ⊙ **If you *do not* have any medically determinable impairments, we will find that you are not disabled, and your application will be denied.**

Once we determine you have an MDI(s) that could reasonably be expected to cause your symptoms, such as pain, we look at the intensity and persistence of your symptoms. We consider all available evidence from your medical sources and nonmedical sources about how your symptoms affect you. Nonmedical sources may include you (the applicant), teachers, social workers, family members, caregivers, friends, neighbors, employers, and clergy.

Your MDI must significantly limit your physical or mental ability to do *basic work-related* activities for a continuous period of at least 1 year (12 months) or result in death.

If it does, we find that your medical condition is *severe*. If you have multiple medical conditions, we consider the combined effect of your conditions at this step and throughout the disability evaluation process. In this document, we use the term “condition(s)” to show that we consider the combined effect of all your MDIs.

When we talk about *basic work activities*, we mean the abilities needed to do most jobs, such as lifting, standing, walking, sitting, or remembering.

⊖ **If your medical condition(s) is *not severe*, we will find that you are not disabled, and your application will be denied.**

➤ **If your medical condition(s) is *severe*, we will continue to step 3.**

Example: Jane lost the sense of taste after a viral illness. Jane has no other symptoms or limitations that lasted or are expected to last for a continuous period of at least 1 year. Because tasting is not a basic work activity, Jane’s condition is not severe. Jane’s application would be denied at step 2.

Example: John has significant limitations in the ability to stand and walk because of chronic pain and fatigue from sickle cell anemia. Because John has significant limitations in basic work activities, John’s condition is severe. The evaluation of disability will continue to step 3.

Example: Jessica broke their wrist. Jessica had to wear a cast and was unable to work for about 4 months. However, the wrist healed, and Jessica was able to return to work without limitation after 5 months. Because this impairment did not significantly limit basic work activities for a continuous period of at least 1 year, it is not severe. Jessica’s application would be denied at step 2.

### **Step 3: Does your condition satisfy the criteria in the listing of disabling conditions?**

Our “Listing of Impairments” (“listings”) describes medical conditions, including sickle cell disease, that we consider severe enough to prevent a person from doing *any* gainful work activity. If your condition satisfies the listing criteria, we will find you disabled at step 3. Each listing explains the medical findings and other requirements needed to satisfy the listing.

Part A of the Listing of Impairments lists the criteria that apply to adults age 18 and over. There are 14 major body systems in Part A, and each body system has a name and number. For example, the “Hematological Disorders” body system covers diseases related to blood and is numbered “7.00.” One of the listings in that body system is “listing 7.05.” Listing 7.05 covers “hemolytic anemias,” including sickle cell disease. Visit [www.ssa.gov/disability/professionals/bluebook/AdultListings.htm](http://www.ssa.gov/disability/professionals/bluebook/AdultListings.htm) for more information.

#### **Examples of Listing Criteria That May Apply to Sickle Cell Disease**

Note: For **SOME** listings, your condition only needs to meet or medically equal **ONE** of the criteria for you to be found disabled at step 3, even though several criteria are listed. For example, listing 7.05 requires *either 7.05A or 7.05B or 7.05C*. When we use the word “or,” that means that only one of those criteria needs to be present. So, in the example, if only 7.05A is present, the listing is met.

The examples below explain the most relevant parts of the criteria and how they relate to sickle cell disease. We also explain what we mean by “medically equals” the listing criteria later in this document. The detailed criteria for each listing below are available at [www.ssa.gov/disability/professionals/bluebook/AdultListings.htm](http://www.ssa.gov/disability/professionals/bluebook/AdultListings.htm).

## ***Listing Criteria in the Hematological Disorders Body System***

Listing 7.05A – sickle cell disease with 6 documented painful crises in 1 year, each requiring intravenous (IV) or intra-muscular (IM) narcotic medication, and each crisis at least 30 days apart.

Listing 7.05B – sickle cell disease with complications requiring 3 hospitalizations in 1 year, each 30 days apart and each lasting at least 48 hours.

Listing 7.05C – sickle cell disease with blood tests showing hemoglobin values at or below 7 grams per deciliter (g/dL), measured at least 3 times in 1 year and at least 30 days apart.

Listing 7.17 – sickle cell disease treated with bone marrow or stem cell transplantation.

Listing 7.18 – repeated complications of sickle cell disease causing significant, documented symptoms or signs (for example, pain, severe fatigue, malaise, fever, night sweats, headaches, joint or muscle swelling, or shortness of breath), AND marked limitations in one area of functioning (activities of daily living, maintaining social functioning, or completing tasks in a timely manner because of deficiencies in concentration, persistence, or pace).

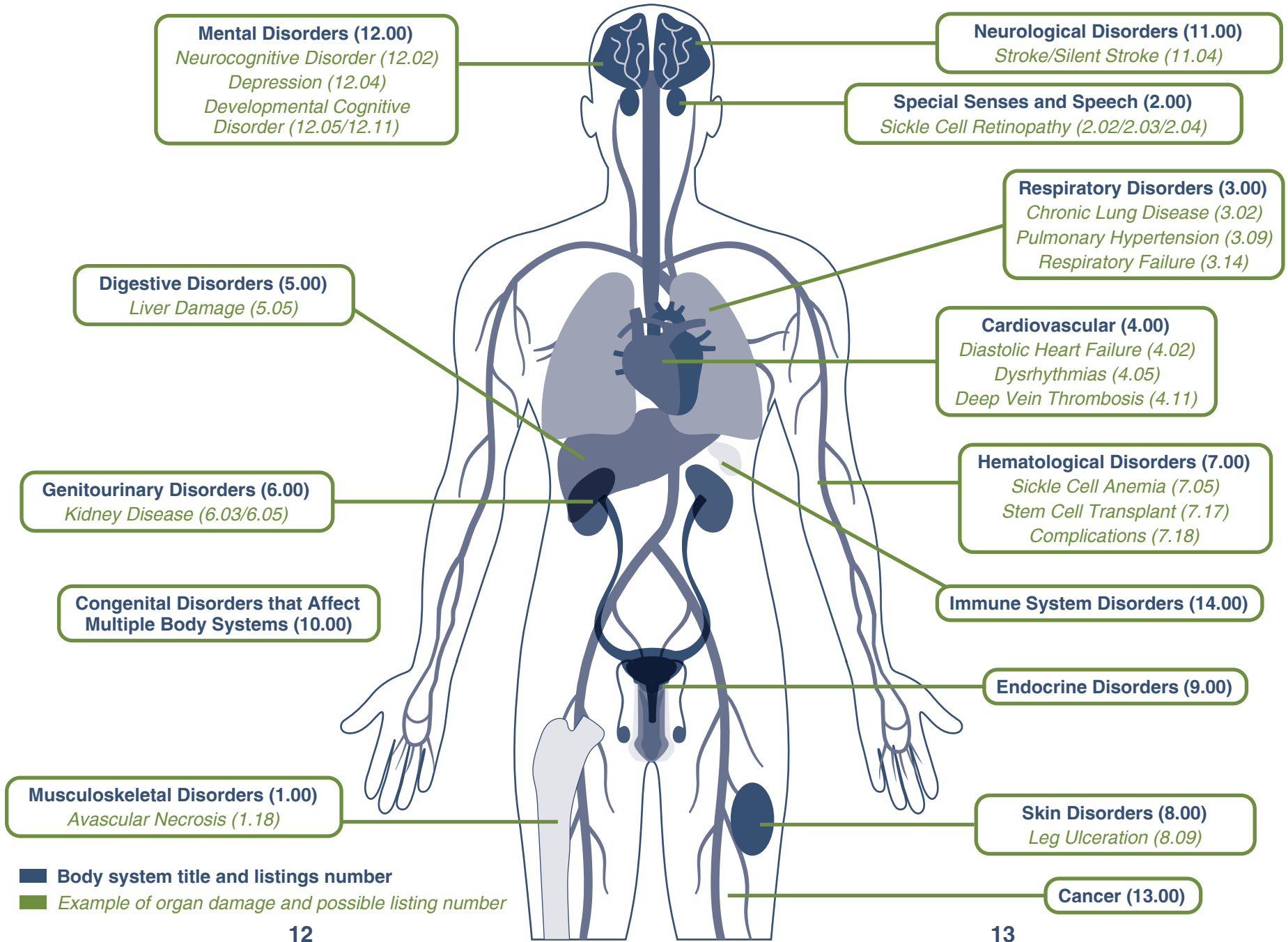
These are only common examples of listings in the hematological body system. If your condition(s) does not meet any of the listings in this body system, we will also consider whether you have a condition(s) that satisfies the criteria of a listing in another body system.

## Other Listings That May Apply to Complications from Sickle Cell Disease

<b>Complication</b>	<b>Possible Listing</b>	<b>Brief Description</b>
Avascular necrosis	1.18	Abnormality of a major joint documented by certain symptoms and medical findings, resulting in certain functional limitations
Sickle cell retinopathy	2.02	Loss of central visual acuity (20/200 vision or less in the better eye)
	2.03	Contraction of visual fields in the better eye with certain documented measurements
	2.04	Loss of visual efficiency in the better eye with certain documented measurements
Chronic lung disease	3.02	Chronic respiratory disorder with certain findings on pulmonary function tests or a required number and severity of exacerbations (attacks)
Pulmonary hypertension	3.09	Chronic pulmonary hypertension documented by pulmonary artery pressure determined by cardiac catheterization
Respiratory (lung) failure	3.14	Respiratory failure from a chronic respiratory disorder (other than cystic fibrosis) needing certain treatments twice in 1 year
Diastolic heart failure	4.02	Chronic heart failure while on prescribed treatment (with certain measurements on cardiac imaging) and either: three episodes of acute heart failure in 1 year, certain exercise test results, or symptoms that make an exercise test dangerous
Dysrhythmias	4.05	Certain recurrent arrhythmias resulting in episodes of cardiac syncope (fainting) or near syncope documented by laboratory testing

<b>Complication</b>	<b>Possible Listing</b>	<b>Brief Description</b>
Deep vein thrombosis (DVT)	4.11	Chronic venous insufficiency of a leg causing extensive brawny edema or recurrent or persistent ulcerations
Liver damage	5.05	Chronic liver disease with certain complications or lab test values
Kidney disease	6.03	Chronic kidney disease with chronic hemodialysis or peritoneal dialysis
	6.05	Chronic kidney disease with certain lab test values and complications
Leg ulcers	8.09	Chronic skin lesions or contractures causing chronic pain or other physical limitations and certain functional limitations
Stroke, Silent stroke	11.04	Vascular insult to the brain, with certain long-term impacts on speech or speech processing, motor function, or certain functional limitations
Neurocognitive disorder	12.02	Documented decline in cognitive function, resulting in marked and extreme functional limitations or marginal adjustment
Mood disorder (depression)	12.04	Depressive, bipolar, and related disorders, documented by symptoms and medical signs, and resulting in marked and extreme functional limitations or marginal adjustment
Developmental cognitive disorder	12.05	Intellectual disorder beginning before age 22 with significantly subaverage general intelligence (generally based on IQ scores) and significant functional deficits
	12.11	Neurodevelopmental disorder resulting in marked and extreme functional limitations and either: attention deficit, hyperactivity, significant learning difficulties, or recurrent movements or vocalizations

# Major Body Systems and Examples of Listings Applying to Common Complications of Sickle Cell Disease



## What if your condition does not meet the requirements of a listing but is still severe?

If your condition(s) does not meet a listing, we will consider whether it *medically equals* a listing. Your condition(s) medically equals a listing if it is at least equal in *severity* and *duration* to the criteria of any listing.

We can find medical equivalence in any of three ways:

1. If there is a listing that applies to your condition, but one or more of the required findings is missing or is not as severe as the criteria requires, and other findings related to your condition are at least of “equal medical significance” to the missing criteria.
  2. If you have a condition(s) that is not described in any listing, and the findings related to your condition(s) are at least of “equal medical significance” to the required findings of a similar listing.
  3. If you have a combination of conditions, but none of your conditions meet a listing by themselves, and the findings related to your combined conditions are at least of “equal medical significance” to the criteria of a similar listing.
- **If your condition(s) *meets or medically equals* a listing, we will find you disabled at step 3.**
- **NOTE:** *If your condition(s) does not meet or medically equal a listing at step 3, this does NOT necessarily mean that you are not disabled. We will continue to evaluate your application. We will go on to step 4 and, if necessary, step 5 of the disability evaluation process.*



## **Steps 4 and 5: Can you do your past work or adjust to other work?**

If your condition(s) does not meet or medically equal a listing, we determine your residual functional capacity (RFC). The RFC is a description of the physical and mental work functions you can still do in a work setting on a sustained basis. The RFC is the most you can do despite the limitations caused by your condition(s).

Examples of work-related functions include:

- Physical abilities: walking, standing, sitting, lifting, pushing, pulling, reaching, carrying, and handling.
- Mental abilities: using appropriate judgment; understanding, remembering, and carrying out simple instructions; and responding appropriately to supervision, co-workers, and usual work situations, including changes in a routine work setting.

We base the RFC on all the relevant evidence in the record, including the effects of treatment. In assessing the RFC, we consider all your work-related limitations, whether due to sickle cell disease, other condition(s), or a combination of your conditions.

We consider all your symptoms, including pain, and whether your symptoms are reasonably consistent with the medical and nonmedical evidence. We also consider all your statements about your symptoms. We consider any description your medical or nonmedical sources may provide about how your symptoms affect your daily activities and ability to work.

Statements about your pain, fatigue, or other symptoms will not alone establish that you are disabled – they must be supported by the evidence.

Example: A person with sickle cell disease may have frequent pain, fatigue, and shortness of breath. This may affect their ability to stand and walk. They may also

experience repeated pain crises. Their pain could make it hard to concentrate and complete tasks, and they may have frequent absences from work. These functional limitations, if supported by the evidence in the record, would be included and described in their RFC.

We use your RFC to determine whether you can do your past work or adjust to any other type of work at steps 4 and 5 of the disability evaluation process.

#### **Step 4: Can you do the work you did previously?**

At this step, we decide if your medical condition(s) prevents you from performing any of your past relevant work (PRW). PRW is defined as work you have done within the past 5 years, that was performed at SGA level, and that lasted long enough for you to learn how to do it. We compare your RFC to the functions required to do your PRW.

- ⊗ **If you *can* do any of your PRW, we will find you not disabled and deny your application at this step.**
- ➡ **If you *cannot* do any of your PRW, or you do not have any PRW, we will continue to step 5.**

#### **Step 5: Can you adjust to other work?**

If you cannot do the work you did in the past, we look to see if you can adjust to other work existing in significant numbers in the national economy despite your medical condition(s).

We consider your medical conditions, RFC, age, education, past work experience, and any skills you may have that can transfer to other work.

- **If you *cannot* adjust to other work, we will find you disabled at step 5.**
- ⊗ **If you *can* adjust to other work, we will decide that you do not have a qualifying disability, and your claim will be denied at step 5.**

For additional information on steps 4 and 5 of the disability evaluation process, see: SSA's Medical and Vocational Quick Reference Guide at <https://secure.ssa.gov/apps10/poms.nsf/lrx/0425001001>

## Resources

- *Sickle Cell Disease and the Social Security Disability Evaluation Process for Children* (Publication No. 60-004)
- *Disability Benefits* (Publication No. 05-10029)
- *Adult Disability Starter Kit* (Publication No. 64-110)
- *Your Right to Representation* (Publication No. 05-10075)
- *If You Are Blind or Have Low Vision—How We Can Help* (Publication No. 05-10052)
- *Apply Online for Disability Benefits* (Publication No. 05-10550)
- *Working While Disabled: How We Can Help* (ssa.gov) (Publication No. 05-10095)
- *Red Book* (A Guide to Work Incentives and Employment Supports for People Who Have a Disability Under the SSDI and SSI Programs) (Publication No. 64-030)
- Blue Book (Listings) (Disability Evaluation Under Social Security). This is also known as the Blue Book. It was made for doctors and other medical providers. It has the listing of impairments for adults and children. See <https://www.ssa.gov/disability/professionals/bluebook/> for more information.
- Other SSA Disability Publications can be found at <https://www.ssa.gov/pubs/index.html?topic=Disability>

## List of Abbreviations

Abbreviation	Definition
DDS	Disability Determination Services
MDI	Medically Determinable Impairment
PRW	Past Relevant Work
RFC	Residual Functional Capacity
SGA	Substantial Gainful Activity
SSDI	Social Security Disability Insurance
SSI	Supplemental Security Income

## Tips for Helping with the Disability Evaluation

- Use the checklists, worksheets, and other information in the *Adult Disability Starter Kit* (Publication No. 64-110) to help you get ready for your disability interview or online application, which can be found at <https://www.ssa.gov/apply>.
  - Note: Plan to spend at least an hour, in total, completing your application.
  - Tip: If completing an application on your own is a burden or if you have questions, you can apply by phone or in person at any Social Security office. You can find your nearest Social Security office through our Social Security Office Locator at <https://secure.ssa.gov/ICON/main.jsp>. Call **1-800-772-1213** to make an appointment. Community organizations, like your local sickle cell disease advocacy organization, may also be able to help.

- Submit an Adult Disability Report (Form SSA-3368-BK) when you apply and include details about your conditions, symptoms, treatment, and functional limitations.
- Complete and submit any forms we send you, such as the Function Report (Form SSA-3373) and Work History Report (Form SSA-3369-BK), as soon as possible.
- Tell us as much as you can about your medical condition(s) and how it impacts you:
  - Explain how your treatment affects your function.
    - Tell us about medications you take, procedures you get (such as blood transfusions), and other therapies, like massage or physical therapy.
    - Tell us about *long-term treatments* to manage your condition and any *short-term treatments* you need for acute complications.
    - Tell us how treatment improves your function and any burdens or side effects that come with it.
    - Tip: If you have a “pain plan” from your doctor that explains how to treat your pain at home or in the hospital, share it with us.
  - Describe your symptoms of sickle cell disease and its complications.
    - Tell us about any pain, fatigue, shortness of breath, mental symptoms (for example, memory loss, difficulty concentrating, anxiety, or depression), or other symptoms.
    - Tell us how often you experience them, and how intense they are.
  - Describe any sickle cell crises or pain crises you had for at least the past year.

- Explain how long they last(ed), how often they happened, and the intensity of your pain, fatigue, shortness of breath, or other symptoms.
  - Tell us about any complications or organ damage that happened.
  - Tell us the dates and providers for any medical treatment you got.
  - Tip: If you have a “pain diary,” or other record of your symptoms and daily activities during your pain crises, send a copy to us.
- Explain how your symptoms, including the side effects of your treatment, impact your physical and mental ability to function, including your ability to:
- attend school or work,
  - perform your daily activities,
  - move around,
  - use your hands and arms,
  - pay attention and concentrate,
  - interact with others,
  - handle stress, and
  - tolerate environmental conditions like heat or humidity.
- Give us the dates of visits to doctors or hospitals and the name of the office or hospital.
    - If you have them, give us the patient account numbers for any doctors or hospitals and any other information that will help us get your medical records.
  - Send us copies of any medical reports or information you already have.
    - NOTE: You do not need to request information from your doctors. We will contact them directly for reports or information that we need.

- Let us know if something changes after you submit your application – for example, if you are hospitalized or have new complications or new organ damage.
- You can give us the suggested information in many ways. For example, you can include it in (or attach it to) your Disability Report or other forms, share it when you talk to us on the phone or at the field office, or mail or fax it to us. You can find the local office fax number and address from the Social Security Office Locator page, which can be found at <https://secure.ssa.gov/ICON/main.jsp>.

### Disability Application Myths and Facts

<p><b>Myth:</b> If I don't understand something or if my application was denied initially, there is nothing I can do.</p>	<p><b>Fact:</b> Visit our website at <a href="http://www.ssa.gov">www.ssa.gov</a> or call 1-800-772-1213 and make an appointment at the field office to get more information. Write down your questions beforehand and bring a friend or family member if helpful. Local community organizations may also be able to help.</p> <p>For more information on appealing a denial, visit our website at <a href="https://www.ssa.gov/ssi/text-appeals-ussi.htm">https://www.ssa.gov/ssi/text-appeals-ussi.htm</a>.</p>
<p><b>Myth:</b> The Social Security Administration only needs my medical information.</p>	<p><b>Fact:</b> Provide us with all the information about your condition(s) and how it affects your ability to work or perform your daily activities. We will consider your descriptions, explanations, pain diaries, home pain plans, "third party reports" from those who observe you, and other information you can provide, because these are all important.</p>
<p><b>Myth:</b> I do not need to complete forms or respond to every request for information.</p>	<p><b>Fact:</b> Complete the <u>Adult Disability Report</u> (Form SSA-3369-BK) when you file your application and return any forms we send as soon as possible. Let us know right away if your contact information changes.</p>

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## Contact Us

There are several ways to contact us, such as online, by phone, and in person. We're here to answer your questions and to serve you. For nearly 90 years, we have helped secure today and tomorrow by providing benefits and financial protection for millions of people throughout their life's journey.

### Visit our website

The most convenient way to conduct business with us is online at **[www.ssa.gov](http://www.ssa.gov)**. There are several things you can do online:

- Apply for Extra Help with Medicare prescription drug plan costs.
- Apply for most types of benefits.
- Start or complete your request for an original or replacement Social Security card.
- Find copies of our publications.
- Get answers to frequently asked questions.

When you create a personal *my* Social Security account, you can do even more.

If you live outside the United States, visit **[www.ssa.gov/foreign](http://www.ssa.gov/foreign)** to access our online services.



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## Call us

If you cannot use our online services, we can help you by phone when you call our National toll-free 800 Number. We provide free interpreter services upon request.

You can call us at **1-800-772-1213** — or at our TTY number, **1-800-325-0778**, if you're deaf or hard of hearing — between 8:00 a.m. – 7:00 p.m., Monday through Friday. For quicker access to a representative, try calling early in the day (between 8 a.m. and 10 a.m. local time) or later in the day. **We are less busy later in the week (Wednesday to Friday) and later in the month.** We also offer many automated telephone services, available 24 hours a day, so you may not need to speak with a representative.



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