



# Sickle Cell Disease: A Guide for Health Professionals on Providing Medical Evidence for Social Security Disability Claims

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This guide for health professionals describes the kinds of medical evidence the Social Security Administration (SSA) needs to evaluate disability claims filed by individuals with sickle cell disease. We appreciate you providing us timely medical records and laboratory reports and other information about the individual's condition.<sup>1</sup> You may send us medical **records electronically, on our secure website at <https://www.ssa.gov/ere/>**, or by fax or mail.

## SSA Definition of Disability

Congress established a strict definition of disability in the Social Security Act. While some programs provide partial or short-term disability payments, SSA's **disability programs** do not.

We consider an adult disabled if the individual is unable to do any substantial gainful work activity because of any medically determinable physical or mental impairment(s) that has lasted, or can be expected to last, for a continuous period of at least 12 months, or that is expected to result in death. We consider a child under the age of 18 disabled if the child has a medically determinable physical or mental impairment(s)

<sup>1</sup> An individual applying for disability benefits must inform SSA about or submit all evidence known to them that relates to whether or not they are disabled. See **20 CFR 404.1512** and **20 CFR 416.912**. By providing us with complete medical records, you are helping individuals fulfill their duty to provide all known evidence relating to whether they are disabled.

that causes marked and severe functional limitations, and that has lasted, or can be expected to last, for a continuous period of at least 12 months or that is expected to result in death.

The medical impairment(s), or medical condition(s), must be shown to exist by medically acceptable clinical and laboratory findings. Under the law, symptoms alone cannot be the basis for a finding of disability, although the effects of symptoms may be an important factor in deciding whether an individual is disabled.

## Step-by-Step Disability Evaluation

We evaluate disability claims using a step-by-step evaluation process. We first confirm that the individual is not performing substantial gainful work activity (Step 1). Then we confirm the medical severity of the individual's impairment(s). The individual must have a medical impairment documented by medically acceptable clinical and laboratory findings that has lasted or is expected to last at least 12 months, or that is expected to result in death, and that is severe. By severe, we mean that the impairment, or a combination of impairments, causes more than minimal limitations in function (Step 2).

Next, we consider whether the individual's medical impairment(s) meets or medically equals (meaning it is at least equal in severity and duration to) the criteria of a listing in one of the 15 body systems evaluated in the **Listing of Impairments** (Step 3). The Listing of Impairments describes for each of the

major body systems the impairments (and the associated medical and other findings) that we consider to be severe enough to prevent an individual from doing any gainful work. The table shows examples of the body systems and some of the complications of Sickle Cell Disease that may meet or equal listing criteria.

### Examples of Listings that May Apply to Complications from Sickle Cell Disease

	Body System	Corresponding Complications and Possible Listings
	<b>Musculoskeletal Disorders (1.00)</b>	Avascular necrosis (1.18)
	<b>Special Senses and Speech (2.00)</b>	Sickle Cell Retinopathy (2.02, 2.03, 2.04)
	<b>Respiratory Disorders (3.00)</b>	Chronic Lung Disease (3.02) Pulmonary Hypertension (3.09) Respiratory Failure (3.14)
	<b>Cardiovascular (4.00)</b>	Diastolic Heart Failure (4.02) Dysrhythmias (4.05) Deep Vein Thrombosis (4.11)
	<b>Digestive Disorders (5.00)</b>	Liver damage (5.05)
	<b>Genitourinary Disorders (6.00)</b>	Kidney disease (6.03, 6.05)
	<b>Hematological Disorders (7.00)</b>	Sickle cell anemia (7.05) Stem cell transplant (7.17) Complications from sickle cell disease (7.18)
	<b>Skin Disorders (8.00)</b>	Leg ulceration (8.09)
	<b>Neurological Disorders (11.00)</b>	Stroke, Silent Stroke (11.04)
	<b>Mental Disorders (12.00)</b>	Neurocognitive Disorder (12.02) Depression (12.04) Developmental Cognitive Disorder (12.05, 12.11)

**If the individual's impairment(s) meets or medically equals a listing, we will find that individual disabled.** If not, we will continue to evaluate the impact of the medical impairment(s) on an individual's ability to function.

For adults, if an impairment does not meet or medically equal a listing, we will determine whether the individual is able to perform work they did in the past or adjust to other work that exists in the national economy based on their age, education, work background, and impairment-related limitations (Steps 4 and 5). **If the individual is not able to perform their past work or adjust to other work, we will find that individual disabled.** If the individual can perform past work or adjust to other work, we will find them not disabled.

For children under 18, if the impairment(s) does not meet or medically equal a medical listing, we evaluate whether their impairment(s) "functionally equals the listings," meaning that their impairment(s) must result in "marked" limitations in two domains of functioning or an "extreme" limitation in one domain. If a child under age 18 has a functional limitation because of their medical impairment(s), we consider their functioning in relation to other children of the same age who do not have the medical impairment(s). **If the child's medical impairment(s) functionally equals the listings, we will find that child disabled.** If the child's medical impairment(s) does not functionally equal the listings, we will find them not disabled.

You can find more detailed information on the ***Disability Evaluation Under Social Security*** page on the Medical/Professional Relations section of our website: <https://www.ssa.gov/disability/professionals/bluebook/index.htm>

## What We Need from You

We need information from you that will help us determine the existence, severity, and duration of the individual's medical condition(s) and its impact on the individual's function.

**Medical reports you provide to us should include a thorough description of the individual's medical history with information on the diagnosis, onset, and duration of the individual's condition(s), and prognosis.**

Longitudinal clinical records and detailed historical notes discussing the course of the condition(s), including any treatment prescribed and the individual's response to treatment, are very useful for us because we are interested in the impact of the illness over time. This will also help us determine when the sickle cell disease or associated conditions became disabling (the disability "onset"). Establishing the correct disability onset date is important because it may affect when cash benefits and Medicare coverage begin.

Medical reports should also describe the standard positive and negative findings of a thorough physical or mental examination, consistent with accepted medical practice. It is essential that you submit all available objective (clinical and laboratory) findings concerning your patient's condition, even if the findings may relate to another disorder or establish that the individual has a co-occurring condition.

**Please include in your reports laboratory findings, observed medical signs, and symptoms or other effects of sickle cell disease, including your patient's statements and descriptions of the frequency and intensity of their sickle cell crises.** Examples may include:

### **Laboratory findings:**

- Abnormal blood tests (e.g. hemoglobin, coagulopathy);
- Radiographic or other imaging abnormalities;
- Results of spirometry or other pulmonary function testing;
- Findings from procedures such as cardiac catheterization; or
- Pertinent microbiology and pathology reports.

### **Medical signs:**

- Dyspnea, tachypnea, hypoxemia, or other respiratory abnormalities;
- Edema;
- Dactylitis;
- Lethargy;
- Priapism;
- Weight loss, delayed growth, or malnutrition;
- Heart palpitations, abnormal blood pressure, arrhythmias, or other cardiovascular abnormalities;
- Palpable enlargement of organ;
- Swelling or tenderness;
- Retinopathy or other abnormalities in the eyes;
- Weakness, numbness, or other focal neurological signs;
- Skin abnormalities, such as pallor, jaundice, erythema, or presence of ulcers; or
- Mental abnormalities, such as cognitive impairment or difficulty concentrating.

### **Symptoms:**

- Acute or chronic pain;
- Difficulty breathing or shortness of breath;
- Cough or wheeze;
- Decreased exercise tolerance;
- Heart palpitations;
- Constitutional symptoms such as fever, weight loss, fatigue, malaise, weakness, dizziness, or headache;
- Chest tightness, pain, or tenderness;
- Sleep problems;
- Changes in vision;
- Cognitive impairment(s) such as having difficulty with information processing, memory, or concentration and attention; or
- Mood changes and new or worsening depression or anxiety.

For more information on potential symptoms of sickle cell disease, see Sickle Cell Disease - Symptoms | NHLBI, NIH at <https://www.nhlbi.nih.gov/health/sickle-cell-disease/symptoms>

### **Helpful Information for Medical History:**

Include as much information as you can about the individual's medical condition(s) in the medical history. Specifically, the following types of information can assist us in evaluating their condition and its impact:

- **Sickle Cell Crises:** A description of any sickle cell crises, including how long they lasted; how often they occurred; the intensity of the individual's symptoms; and any resulting complications or organ damage, for at least the last 12 months;
- **Effect of Treatment:** Information about the effect of treatment (including long-term treatments to manage the conditions and any short-term treatments required for acute complications) on the individual's function – both how it improves function and the burden or side effects;
- **Description of Symptoms:** A description of the individual's pain, fatigue, or other symptoms of sickle cell disease and its complications, including the frequency and intensity of these symptoms; and
- **Functional Impact:** An explanation of how the individual's long-term symptoms and the acute crises they experience, as well as the treatment they receive, impact their ability to function, perform activities of daily living, or attend work or school.

### **Opinion and Functional Ability:**

Your descriptions of any functional limitations you noted throughout the time you examined or treated your patient are very important. **If possible, please provide your opinion of the individual's ability to do daily activities or work-related physical and mental activities.**

Tell us your opinions about what the individual can still do despite their impairment(s) and whether they have impairment-related limitations in work-related functions. Please be sure to tell us the reason for your opinions, such as clinical findings and your observations of the individual.

Examples of work-related functions include:

- **Physical functions:** The ability to walk, stand, sit, lift, push, pull, reach, carry, and handle.

- **Mental functions:** The ability to understand, remember, and carry out simple instructions; the ability to use appropriate judgment; and the ability to respond appropriately to supervision, co-workers, and usual work situations, including changes in a routine work setting.

## Evaluating Disability for Individuals with Sickle Cell Disease

State agencies called Disability Determination Services (DDS) make disability determinations for SSA. The DDS uses an adjudication team that consists of a physician or psychologist and a specially trained disability examiner to decide whether an individual is disabled under Social Security law. In evaluating disability for individuals with Sickle Cell Disease, the team looks at all the available evidence, including the clinical course from the onset of the illness, and considers the impact of the disease on each affected body system.

If the team determines they need more information to make a determination, they may call or write to you to ask if you have that information. If you do not, they may ask you or, in some circumstances, an independent medical source, to provide the information by performing tests or an examination paid for by the DDS.

For more information on how we evaluate disability cases with Sickle Cell Disease, see **Social Security Ruling (SSR) 17-3p, Titles II and XVI: Evaluating Cases Involving Sickle Cell Disease (SCD)**.

## Contacting Social Security

The most convenient way to contact us anytime, anywhere, is to visit [www.ssa.gov](http://www.ssa.gov), where you can also access many of our services with an online *my* Social Security account.

We look forward to serving you.



Securing today  
and tomorrow

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