



Frequently Asked Questions

The New Social Security Rules – Addressing Presumptive Disability for People Living with ALS

1. What do the new rules mean for people living with ALS?

The new rules do two things: 1) they change the listing for ALS to make it easier to qualify for social security disability insurance (SSDI) under the listings, and 2) they add ALS to a special list of conditions that automatically qualify for “presumptive disability” payments under Supplemental Security Income (SSI).

2. What are the listings?

The Social Security Administration (SSA) maintains a “Listing of Impairments” that is divided into major body systems, like neurological and musculoskeletal. The Listing of Impairments, or “listings,” is a section of SSA’s regulations that describes medical conditions that are so severe that SSA deems automatically that a person is disabled.

ALS has been included in the neurological body system section of the listings for many years. But in the past, the listing for ALS also required certain serious physical findings associated with more advanced disease to establish disability under the listing. Under the prior listing for ALS, a person applying for benefits needed to demonstrate that they had ALS *and* significant “bulbar” signs, such as difficulty swallowing and speaking, or significant interference with their ability to use their arms or legs. If their ALS was not that severe, they could show disability at another step in the 5-step process. The 5-step process is the decision process the SSA goes through to determine whether or not a person is disabled. This process is outlined below in another FAQ.

Under the new listing for ALS that SSA published in August 2003, only medical evidence demonstrating that the person has ALS is needed to meet the listing and to be found disabled.

SSA has many other listings. If a diagnosis of ALS is not shown by medical evidence, a neurological or other condition may still exist that meets the requirements of one of SSA’s other listings. Also, if the condition does not meet the requirements of one of SSA’s listings, a person may demonstrate that their condition is just as medically disabling as one of the listed conditions. SSA calls this “equaling a listing.” SSA also considers the combined effects of multiple medical conditions.

3. Where can the ALS listing be found?

This link, <http://www.gpoaccess.gov/fr/index.html>, will take you to a web site where you can find more information on the ALS listing. Type “ALS” into the search box and click on “submit.” Then choose one of the three viewing options under the first item on the search results page.





The ALS listing is listing 11.10. There is also explanatory information about what evidence is needed in section 11.00G, which is in the introduction to the listings.

SSA uses the listings only to find that people are disabled. When people have conditions that do not meet or equal the requirements of a listing, SSA can still find disability based on other factors, which are presented later in this document.

4. What do the new rules *not* do?

The new rules do not change any other requirements of the Social Security Disability Insurance or SSI programs. For example, they do not change any of the rules for how much work coverage is needed to qualify for SSDI or how much money can be earned in order to qualify under the law as disabled.

The rules also do not affect people with other diagnoses. One, however, can still qualify if their medical condition is serious enough even if it is not diagnosed as ALS. For example, if someone has lower motor neuron disease that has progressed significantly, SSA has another listing that this person may qualify under; or this person may qualify at the last step of the determination process even if it is not as serious as a condition in the listings.

5. What kinds of disability benefits does Social Security provide?

SSA pays disability benefits under two programs: the SSDI and SSI.

SSDI: Entitlement to SSDI is based on work on which FICA taxes are paid. People with ALS who qualify for SSDI also qualify for Medicare as soon as they are entitled to benefits.

- Before deciding whether or not to apply for SSDI, it is recommended for individuals who currently have insurance coverage to review their health plan summary of benefits. A comparison of both benefit plans can indicate which plan is more appropriate for an individual's specific needs. Some people have found that their existing health insurance coverage is better for their health care needs than the coverage provided by Medicare.
- People who are approved for SSDI become eligible for Medicare, Part A (hospital) and Part B (outpatient and doctor fees) five months after the date SSA determines that an individual became disabled. Social Security Administration rules (Policy HI 00801.002) do not allow a person who is eligible for Medicare to waive or decline the Part A (hospital) coverage. There is a premium that must be paid for Medicare Part B (outpatient and doctor fees), and Part B can be waived or declined, without affecting an SSDI claim.
- There are laws that provide guidance as to which insurance plan is "primary" when a person with existing insurance coverage becomes eligible for Medicare. Depending on several criteria, existing insurance could become "secondary" to Medicare, or it could be "primary" and Medicare would be "secondary."





- There are situations in which a person's existing insurance is cancelled when he/she becomes eligible for Medicare. It is best to review the existing health care plan with a health plan customer service representative.

SSI: Eligibility for SSI is based on financial need. In most states, individuals who qualify for SSI also qualify for Medicaid. (Medicaid has different names in some states. For example, it is called “Medi-Cal” in California and “TennCare” in Tennessee).

To find out more, read the two SSA booklets *Disability Benefits* and *Supplemental Security Income*. Both documents are available to read or download on the SSA’s web site at <http://www.socialsecurity.gov/pubs/10029.html> and <http://www.socialsecurity.gov/pubs/11000.html>. Or call SSA at 1-800-772-1213 or TTY 1-800-325-0778 and ask for the pamphlets, which are free of charge. The pamphlets are also available for free at local Social Security offices.

6. When did the new rules go into effect?

The new rules were effective on the day they were published, August 28, 2003.

7. When the new rules went into effect, what happened to ALS patients who were already in the process of filing for benefits?

If a case was already pending at the time the new regulations went into effect, SSA should have applied the new regulations to the entire period covered by the application, even the period before the rules went into effect. If a person is denied benefits, they should appeal that decision.

8. When does entitlement to benefits start?

It depends on the kind of disability benefits that are applied for and when SSA’s standards for disability are first met. For SSDI, one may be able to get benefits for as many as 12 months before the month they applied. For most SSDI claims, there is a five-month “waiting period.” This means that benefit payments begin after the first five months SSA deems someone disabled. So, to get benefit payments for 12 months before an application, SSA would have to find that disability began 17 months before: a five-month waiting period + 12 months’ retroactivity for payments. The waiting period is a requirement in the Social Security law. Retroactive payments for SSDI are available to individuals that qualify for benefits, but they must wait until their application is processed.

For SSI, payments begin during the month that follows the month in which the application was filed. For example, if an application was filed in January, payments would begin in February. There is no waiting period as in SSDI.

9. If someone is found disabled and eligible for SSDI beginning in the past and the five-month waiting period has already ended, do they qualify for Medicare retroactively?





Yes. If a person has ALS, they become entitled to Medicare as soon as they become entitled to SSDI payments—the first month after they have completed the five-month waiting period.

10. What are “presumptive disability” payments?

Presumptive disability (PD) payments are special payments SSA makes *only* under the SSI program. They are payments SSA can make before they determine whether someone qualifies for SSI when there is a high degree of probability that they will find that person disabled when they make their formal decision and the other requirements for SSI eligibility are met. Although any condition that is sufficiently serious can qualify for PD payments, SSA provides a special list to its local offices and the state Disability Determination Services (DDS) of conditions that qualify automatically. Under the new rules, SSA has added an “allegation of” ALS to this list. This means that if someone has ALS and they tell SSA about it when they apply for SSI, SSA can start to provide PD payments right away before the DDS makes its determination whether they qualify for SSI.

SSA can make PD payments only for a maximum of six months, and they cannot make them retroactively. If SSA ultimately determines that an individual does not qualify, the individual will not have to pay back any PD payments that were received.

11. Why doesn’t SSA provide PD payments for SSDI?

The law provides for PD payments only under the SSI program.

12. Who can get SSDI?

Most people who get SSDI are workers—both employees and self-employed people—who paid FICA taxes on their earnings and worked long enough to get what SSA calls “insured status.” The amount of completed work needed to get insured status depends on an individual’s age and how much is earned. SSA’s *Disability Benefits* booklet explains in more detail how to earn insured status. It also includes a chart showing how much someone must work depending on his or her age.

13. Is a work history needed to get disability benefits?

There is no work history requirement in SSI, but limited income and assets are necessary to qualify. For more information, see SSA’s *Supplemental Security Income* booklet or contact SSA.

There are also SSDI benefits for some people who have not worked. There is an SSDI benefit for disabled widows, widowers, and surviving divorced spouses of workers who were insured when they died. This benefit applies only to people who are at least 50 years old. Also, there are SSDI benefits for adult disabled children of insured workers who died or who are entitled to SSDI retirement or disability benefits if they have been disabled since before they were 22 years old. For more information, see SSA’s *Disability Benefits* booklet or contact SSA.





Also, if a person has worked and paid FICA taxes in the past but stopped working because of disability, they may still be able to qualify for SSDI if they can show that they were disabled before their insured status ran out. The rules are very complicated. It is always best to contact SSA and to file an application.

14. How does SSA determine disability?

First, file an application with SSA.

In most cases, SSA sends your information to the state DDS. The DDS makes the decision about disability for SSA following SSA's rules. The DDS sends away for medical information from the treating neurologist and other medical sources, if this information hasn't already been provided, and any other information they may need to make the decision. DDS may also ask the individual to go for a medical examination to help them make their decision. The patient will not have to pay for this examination.

15. Should someone wait to get the information from their doctor before they apply?

No. The date a person applies can affect the benefits that are received, so individuals are encouraged to apply as soon as they believe they cannot continue to work. SSA can get the rest of the required information after the application is submitted. Also, SSA can help collect the information needed to complete an application.

16. What are SSA's rules for determining disability?

The rules are the same for SSDI and SSI, except for people who are under 18 and who apply for SSI. SSA uses a five-step process for everyone except people under 18 who apply for SSI; there is a different, but similar process for them. The steps are followed in order. The SSA can reach a decision at any time during the process.

It is important to know about these steps because in some cases it can be shown that a person was disabled even before they had a diagnosis of ALS, or if they have a different diagnosis than ALS. Also, it is important to know that, by law, SSA must always have medical evidence verifying any condition. It is not enough to submit only a doctor's note stating that someone has ALS or another condition, or that an individual is "disabled." The SSA must have the information the doctor used to make the diagnosis of ALS, or a medical report from the doctor reporting those findings.

The 5 steps are:

1. Is the individual participating in "substantial gainful activity"?

If a person is working, they cannot qualify if the work is "substantial gainful activity" (SGA) no matter how seriously their ALS has progressed. SSA generally considers the amount of your earnings to make this decision. In 2003, SSA will determine that SGA is being conducted if earnings average more than \$800 a month. In 2004, the amount will be \$810 a





month. However, SSA does not always count all earnings. If a person is still working and wants to apply, it is best to check with SSA to see if they qualify.

If a person is not working, or his or her earnings are not SGA, SSA goes to the next step.

2. Is the condition "severe"?

The condition must interfere with one's ability to do basic work-related activities to be considered further. If it does not, SSA will find that this person is not disabled. If it does, SSA goes to the next step. If a valid diagnosis of ALS was presented, SSA should always find that a "severe" impairment is present and go to the next step.

3. Does the condition meet or equal the criteria in one of SSA's listings?

Under the new listing SSA published in August 2003, individuals who have a valid diagnosis of ALS shown by medical evidence meet the listing and are disabled.

SSA uses the listings only to find that people are disabled. When people have conditions that do not meet or equal the requirements of a listing, SSA simply goes to the next step.

4. Can this person do work they did previously?

If the condition is severe, but not at the same or equal severity to an impairment in the listings, SSA looks at any existing physical and mental limitations resulting from the condition to determine if this person can still do the work they did previously. SSA counts only work done within the past 15 years. If this work can still be accomplished, the claim will be denied. If it cannot be accomplished, SSA goes to the last step.

5. Can any other type of work be done?

If an individual cannot continue their previous work, SSA decides if they are able to adjust to other work. Physical and mental limitations from your medical conditions and your age, education, and work experience are all factors considered. If it is found that an individual cannot adjust to other work, his or her claim will be approved. If they can, their claim will be denied.

17. What if a person took an early retirement and is now disabled?

Some people who are already receiving reduced retirement benefits from SSA because they filed before their full retirement age may be able to get increased benefits and Medicare if they are disabled. The rules can be very complicated, so it is best to contact the local SSA for information and to file an application for SSDI benefits.

18. What about the widows and widowers that are left without their spouses? Can they go back and reapply for retroactive SS benefits that should have been paid to their spouses before?





If a person's spouse has died within the past three months, they should contact Social Security *immediately*. There are special provisions for filing applications for SSDI for workers who have died, but they *must* be filed within three months after death. Also, if someone's spouse had already filed an application for SSDI or SSI, or started the application process with SSA before he or she died, the widow/widower may be entitled to back benefits. Check with SSA.

19. Will this disability status hinder a person with ALS from continuing to work full-time?

SSA cannot find people disabled if they are working at SGA when they apply. Once people qualify for benefits, there are many provisions that allow them to work or to try working when they are able. See SSA's "Work Site" at <http://www.socialsecurity.gov/work/index.html> for details on the various work incentives under SSDI and SSI or contact SSA. The new rules do not change these work incentives in any way.

20. If an individual was diagnosed almost 2 years ago, can they apply for SSI disability now even though they are still working 40 hours a week?

If an individual is working and the work they are doing is SGA, they cannot qualify no matter how serious their ALS is. If they are working but are not doing SGA, or if they are not sure whether they are doing SGA, they should contact SSA.

21. How can a person apply?

Individuals can apply for Social Security benefits by telephone, by mail, in person, and in some cases even online. To apply by telephone, call toll-free at 1-800-772-1213 or TTY 1-800-325-0778, Monday-Friday, 7am-7pm Eastern Time. The SSA representative at the 800-number can make an appointment to apply by telephone or can make an appointment to apply at your local Social Security office. Find local Social Security offices at <http://www.socialsecurity.gov/locator/>. Applications for SSDI can be submitted on Social Security's web site at: <https://s3abaca.ssa.gov/pro/isba3/wwwrmain.shtml>.

For assistance with making an application to Social Security, contact the A.C.C.E.S.S. program at 1-888-700-7010. The representative will ask for the applicant's social security number, name and address. Additional information that the applicant will eventually need to provide to SSA includes, but is not limited to: birth certificate; names and addresses of hospitals and physicians; medications; marriage information; dependent children's names, along with their addresses and social security numbers; employers over the last 15 years; and income. But remember, it is important to start the application process as soon as possible. SSA does not require waiting until all this information is gathered to start the application.

22. How long will it take to get a decision?

On average, it takes about three months to get a decision. However, this is only an average. Experiences can be shorter or longer.





Important: SSA has an expedited procedure for processing terminal illness cases to ensure that a favorable decision can be made as quickly as possible. The code word for this type of case is “TERI” case. A person with ALS, particularly if advanced symptoms are present, should advise SSA of this fact at the time of application and ask to have terminal illness case procedures applied.

23. One of the many concerns for people living with ALS is the high cost of the drug Rilutek (approximately \$800 per month). Does SSA provide any assistance for prescriptions?

SSDI entitlement will provide some income and entitlement to Medicare, but Medicare will not cover the cost of drugs. Congress has passed both a House and Senate version of a Medicare Prescription Drug bill that would provide additional assistance to patients who have high annual drug costs. The ALS Association is fighting hard to ensure this legislation is enacted into law, includes a provision for catastrophic coverage, helps to progress the drug discovery process and development of new and better pharmaceutical treatments and is universal.

24. For more information:

Social Security’s web site provides a wealth of information about SSDI, SSI and related matters. Start by going to Social Security’s home page, <http://www.socialsecurity.gov/>. Near the center of the page, click on one of the links under “Disability and SSI” to get started. Be sure to check the “Publications” page for various publications about disability benefits and work incentives, including the booklets already mentioned.

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