

Employment and ALS

Getting diagnosed with ALS can raise many questions about your employment, like how long you should keep working, when you should tell your employer, and what will happen without your health insurance. The answers to these questions will be different for everyone and will depend on factors such as your type of work, progression of the disease, employer, and insurance situation.

Discussing your options with your ALS clinic social worker and team can be very helpful. It is very important that you understand what questions you may need to ask your employer if you are ready to tell them about the diagnosis. Ensuring a smooth transition will take forethought and planning. Your human resources department or point person should be your best reference for understanding your benefits and options.

Will I qualify for disability insurance?

The good news is that most people diagnosed with ALS qualify for Social Security Disability Insurance (SSDI)—even if you are under 65.

SSDI provides monthly income for people who become unable to work due to a disability. It is a federal program that pays disabled people a benefit based on their average lifetime earnings before they were considered disabled. In order to receive SSDI, you must have worked in the last ten years and paid into Social Security for a total of 40 quarters (ten years) or more. You can only apply after your ALS diagnosis and after you stop working.

What about short-term and long-term disability insurance?

Some people purchase short-term or long-term disability insurance policies in addition to their standard health insurance. If you purchased a policy prior to your symptoms and diagnosis—or if your employer automatically enrolled you—then you should receive benefits according to your policy contract.

When you become unable to work, you will receive a monthly check that you can spend on anything. The more you paid in premiums, the greater your reimbursement should be. Short-term policies can last from a few months to a few years. Long-term policies can pay you for many years, or even up to a specified age.

Talk with your human resources department or insurance agent for details about your benefits. Most plans include an elimination period, which is the time between stopping work and beginning to receive benefits. Benefits usually begin after your sick leave time has been used.

What will happen to my health insurance?

If you currently receive health insurance through your employer, chances are you will lose coverage once you stop working. The good news is that if you qualify for SSDI, you should also qualify for Medicare health insurance, which will cover the bulk of your expenses. However, you may also need to purchase private insurance to fill in the gaps.

What if my family is on my employer-based plan?

If you stop working and your family is on your employer's healthcare plan, everyone will need to find new coverage. Unfortunately, this does happen—and monthly premiums will probably be higher for them. If you qualify for Medicare, it will only cover you as an individual.

What if I might have a gap between insurance plans?

There are a few different options for bridging gaps between the day one insurance plan ends and the next one begins:

- **COBRA:** If you are about to lose your employer-based health insurance because you're going to stop working, you can enroll in COBRA, a federal program that allows you (and your family) to remain on your same plan for up to 18 months.
- **Short-term Private Plan:** Whether you were working or not, you can purchase a short-term plan from an insurance company to bridge a waiting period and avoid a gap in coverage. If you are losing coverage through your employer, you can shop around to see whether a short-term plan or COBRA makes more sense for you.
- **Family and Medical Leave Act (FMLA):** If you work for a federal agency, primary or secondary school, or at a company with 50 or more regional employees, you may be eligible for 12 weeks of unpaid, job-protected leave per year. FMLA also requires that your employer continue to provide your same health benefits during this time.

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