



## **Second Opinion Frequently Asked Questions**

### **Why is it important to get a second opinion?**

Your doctor has told you that you have ALS. Getting a second opinion on the diagnosis of a serious and ultimately life-threatening disease like ALS can be critical. Since there is no definitive test for ALS and the symptoms can mimic many other medical conditions, making the diagnosis of ALS can be difficult. Often it is only after the symptoms have progressed and the patient shows conclusive signs and symptoms of the disease that a physician can reach a diagnosis of “definite” ALS. Some neurologists estimate that as many as 15% of the people diagnosed with ALS have been incorrectly diagnosed.

You think you may have the symptoms of ALS, but no one has given you this diagnosis. It is not uncommon to hear of people eventually diagnosed with ALS who had progressive muscle weakness, twitching or cramps for a year or more without knowing what was wrong. In some situations, patients undergo treatments including surgery and other serious and expensive medical interventions for misdiagnosed symptoms. If the symptoms of muscle weakness, twitching or cramps progress despite therapies, or your doctor can't reach a diagnosis, it may be time to get a second opinion. It's important, however, not to become unduly alarmed. ALS is an uncommon disease with only 2 cases diagnosed per 100,000 population each year. This translates into approximately 5,000 new cases of ALS in the U.S. each year.

As quoted from an article in the Los Angeles Times (“Need a Second Opinion?” by Rosie Mestel. Los Angeles Times. February 15, 1999, Home Edition: Health Section, Page S-1), “ ‘ Whenever you have doubts about your care, you should at least think about getting a second opinion,’ says Peter Lee, director of consumer protection programs at the Center for Health Care Rights, a Los Angeles-based consumer advocacy group. ‘Patients aren’t shackled to their doctors. They need to be assertive. They need to be in control of deciding what their care should be.’ ”

### **How to go about getting a second opinion**

First, let your current physician know you'd like a second opinion. Since this is becoming a common occurrence in the U.S. and most doctors truly have your health as their primary concern, you can likely expect your doctor to be open to this idea. However, it's normal to feel a certain amount of reluctance to bring up the question of a second opinion to your doctor. Most Americans have confidence in their health care provider and don't want to risk offending their physician or jeopardizing the relationship they have established.

One of the tips from the Los Angeles Times article suggests, “ ... say something like, ‘You know, this is a complicated and important (issue) for me, and I think I'd like to talk to another physician about my (diagnosis) as well. Perhaps you have a recommendation?’ That helps





preserve the bond', says Peter Clarke, professor of preventative medicine at USC and co-author of "Surviving Modern Medicine."

Next, find a doctor for your second opinion. Since even some neurologists haven't taken care of a patient with ALS, it is important to consider seeing a sub specialist - a neurologist specializing in neuromuscular diseases like ALS. In the approximately 60 ALS clinics across the country, there are physicians knowledgeable and experienced in making the diagnosis of ALS. Your current doctor may be able to recommend someone. Included on ALSA's web site are lists of certified ALSA Centers and ALS clinics working with ALSA chapters. Other places to get information include your local ALS Association chapter or support group, ALSA's national toll-free information and referral service (800) 782-4747 or the many reliable medical Internet web sites. Other sources of information are local hospitals, state medical and neurological associations and the American Academy of Neurology. An advantage of consulting a doctor who treats a number of ALS patients is that he or she is likely to be informed about the latest treatments and current research and can offer a supportive, hopeful perspective.

### **Who pays for a second opinion?**

Before making a final selection on whom to see for your second opinion, review your health insurance policy or contact your health insurance company to find out if the cost of a second opinion is covered under your policy. Also check to learn if there are any restrictions as to which physician can provide a second opinion. Often managed care companies will require that patients to get their second opinion from a doctor who participates in the same managed care plan. The policies on coverage for second opinions vary from state to state and company to company. Some states are considering legislation that would require health care plans to pay for a second doctor's opinion if the patient or primary doctor requests one. Second opinion physician consultations can cost \$150 or more if patients have to pay for the visit themselves. In dealing with health insurance companies, remember that patients have the right to appeal insurance decisions. For more information about appeals in managed health care companies, contact the state Department of Corporations.

### **What to expect at your second opinion appointment**

Let the doctor's office know you are requesting a second opinion for an ALS diagnosis. Many doctors will schedule an appointment for ALS consultation more quickly than routine appointments.

- Often the consulting physician will be able to use the results of test you have already had thus saving money, time and the process of repeating multiple tests. Be sure your complete medical record, results of tests, and actual MRI, CT, or X-ray films and electromyography (EMG) recordings get to the doctor's office before your appointment - or bring them with you. By having the actual results rather than the report of the test, the consulting physician can provide his or her own interpretation of the test results.



# *fyi...* for your information

- It's a good idea to have a relative or friend come with you for support and to take notes on, or tape record, what the doctor says and recommends. Realize that a second opinion appointment can be a stressful time and be sure to write out your questions in advance.
- Since you will likely be seeing an ALS expert, take advantage of the opportunity to ask questions about prognosis (what your future holds), research, treatment, availability of drug trials and, most importantly, how to manage ALS symptoms and maintain your physical function for as long as possible.
- Verify that the consultant will provide a full report to your current doctor and will be available to you for follow up questions. "'Education is empowerment,' says Cedars-Sinai's Beth Karlan, director of gynecologic oncology. 'It's a sound bite, but it's true. It's really important that you view yourself as a consumer of the most important thing in the world - your own life.'"

"Need a Second Opinion?" by Rosie Mestel. Los Angeles Times. February 15, 1999, Home Edition: Health Section, Page S-1.

"Preparing for Your Second-Opinion Visit." By Rosie Mestel. Los Angeles Times. February 15, 1999. Home Edition: Section Health, Page S-5.

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The ALS Association, 27001 Agoura Road, Suite 150, Calabasas Hills, CA 91301-5104,  
Phone: (800) 782-4747 / alsinfo@alsa-national.org / www.alsa.org