



## 2nd Opinion FAQs

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### **Is a second opinion worth the trouble?**

Yes. If a patient wants a second opinion, he or she should get it. I actually recommend getting a second opinion because the diagnosis of ALS is so life changing. The only way a person can begin to accept such a diagnosis is to be certain that the diagnosis is correct.

### **How often is the first diagnosis of ALS wrong and the problem turns out to be something else?**

In about 10 to 15% of the cases, patients get what we call a false positive. That means they are told they have ALS, but, in the end, another disease or condition is discovered to be the real problem.

### **Are some patients told they don't have ALS and then it turns out that they do?**

Yes, up to 40% of patients are initially told they have another disease, and then it turns out they have ALS. Many conditions can mimic ALS.

### **What typically causes a delay in getting the right diagnosis and what is the impact of getting a delayed diagnosis of ALS?**

An international study that surveyed physicians in the United States, Europe and Latin America showed that a delay in diagnosis typically occurs at three key times:

- At the onset of symptoms, some patients take up to six months to see a physician.
- Some patients do not see a neurologist right away, and it may take from three to six or seven months before they do so.
- Sometimes the neurologist doesn't give a diagnosis of ALS because the patient doesn't fulfill all the criteria, is atypical, or hasn't shown any progression of symptoms, and in such cases a delay in diagnosis of 3 to 4 months can occur.

Depending on which of these factors combine, it can take nine to 12 months before a diagnosis of ALS is made.

There is an FDA-approved drug, Rilutek,<sup>®</sup> which has been shown to produce a modest increase in survival. Research indicates that the drug is most beneficial if started early in the course of the disease.





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

First, let your current physician know you'd like a second opinion. Most doctors truly have your health as their primary concern, so 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 tip from a Los Angeles Times article<sup>1</sup> 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 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 many ALS clinics across the country, there are physicians knowledgeable and experienced in making the diagnosis of ALS. Included on The ALS Association's web site are lists of certified ALS Association Centers<sup>SM</sup> and ALS clinics working with ALS Association chapters. Other places to get information include your local ALS Association chapter or support group, The ALS Association's national toll-free information and referral service (800) 782-4747. 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. You can also contact Medicare for specific state rules: 1-800-MEDICARE (1-800-633-4227) or visit <http://www.medicare.gov/coverage/home.asp>.

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.

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





### **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.

It's a good idea to have a relative or friend accompany 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. "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."

