



# Effects of ALS on the Mind: A New Research Study for You and Your Caregiver

Department of Veterans Affairs (VA)

For more information, please contact 857-364-2136



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## Questions We Want to Answer

1. *How does ALS affect changes in your thinking, behavior and mood? Are there risk factors for the development of these changes?*
2. *How do these changes affect your caregiver? Do caregivers have special needs that your healthcare provider should be aware of?*

## How ALS Can Affect Your Thinking and Behavior

This study is investigating whether amyotrophic lateral sclerosis (ALS) can cause problems in thinking, behavior, and mood. We are also interested in learning whether these problems affect caregivers. A caregiver is anyone who regularly cares for a person with ALS, and can be a spouse, an adult child, or other family member.

We will ask you to complete tasks that will help us measure your thinking (such as attention, concentration, and memory), behavior, and mood. Additionally, we will ask your caregiver to complete surveys about you, his/her mood, and the challenges that he/she may face as a caregiver. These tasks and surveys will help us to understand whether there are different patterns of thinking and behavior problems that occur in people with ALS. We will also examine whether thinking and behavior problems are related to greater caregiver burden.

## What can I expect if I take part in this study?

In order to take part in this study, you and your caregiver will both need to participate. After enrollment, you and your caregiver will complete some assessments by telephone and by mail. This may take up to an hour of your time for each of you. About 6 months after the initial assessment, we will ask your caregiver to answer some questions over the phone and complete some brief questionnaires. Your caregiver will answer questions regarding their observations of your thinking, behavior, and mood, as well as whether they are

experiencing any challenges or burdens as a result of caregiving.

A year after enrollment, you and your caregiver will have another telephone interview and be mailed questionnaires similar to the initial assessment. These annual and 6-month follow-ups (caregivers only) will continue for up to 3 years.

### What are the potential benefits of taking part?

You and your caregiver will be compensated \$20 jointly for your time at the start of the study and at each 6-month and yearly follow-up visit. In addition, the results of this research may lead to a better understanding of changes that take place in thinking and behavior in people with ALS, and may help doctors and researchers understand how to better help caregivers and prevent unnecessary stress.

### How to Contact Us

Thank you for thinking about helping us with this important research. Additional information is provided in the **Frequently Asked Questions** section of this brochure. We are always happy to answer any questions you or your caregivers may have. During working hours, you can reach us at our **office number: 857-364-2136**.



U.S. Department  
of Veterans Affairs

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## **Frequently Asked Questions (FAQs):**

### ***Who is able to participate in this study?***

In order to take part in this study, we will need both you and your primary caregiver to participate. A caregiver is anyone who provides care for you on a regular basis. This could be your spouse, your adult child, or other family member who cares for you throughout the day.

### ***Will I need to do any travelling to take part in this study?***

No, this study does not require any travel. All assessments will be done by phone or by mail once per year, or every six months for your caregiver.

### ***I am interested in participating! What's next?***

Great! We are very thankful for your participation. It is important to talk about participation with your caregiver, as he/she will also need to be involved in the study. If you have both discussed this and would like to take part, the next step will be for you to contact us. You or your caregiver may reach us at **857-364-2136** during business hours. If you are trying to reach us outside of these hours, please leave us your name and number and we will call you back the next business day.

### ***How will the information that you collect from me be protected?***

All of the information that is collected from you by our group will be labeled with a code that does not identify you directly, and will be kept confidential as required by law. The results of this study may be published for scientific purposes, but your records or identity will not be revealed unless required by law. Our study complies with the requirements of the Health Insurance Portability and Accountability Act (HIPAA) of 1996 and its privacy regulations and all other applicable laws that protect your privacy.