

# ALD & Neuropsychology FAQs

## Neuropsychology Referrals and Access

### Why am I or my child being referred for neuropsychological assessment?

You or your child could be referred for a neuropsychological assessment for many reasons. Your referring provider will be able to answer this best. If you or your child has received an ALD diagnosis but is asymptomatic, you have likely been referred to understand strengths, weakness, and emotional needs. This assessment is often helpful for establishing a cognitive baseline so if there are any changes in behavior or thinking skills, you or your child can be monitored over time.

If you or your child are receiving treatment for ALD, you have likely been referred to monitor or support cognitive skills or emotional functioning before and after treatment. Some individuals are referred because of difficulties in learning, attention, or behavior. Others may not be reaching developmental milestones or have other diagnosed medical conditions that impact cognitive functioning. Providers also refer people to neuropsychology appointments if they are considering multiple diagnoses and need more information.

### How is neuropsychology used specifically in ALD?

The presentation of ALD varies widely. Individuals may be asymptomatic or have neurological symptoms. Because of this, the test results can be used for different purposes including the following:

1. Establish a baseline of cognitive or behavioral function
2. Evaluate the brain's response to transplant or gene therapy for cerebral ALD
3. Monitor changes in symptoms over time
4. Reveal updated diagnoses or medical recommendations.
5. Maintain up to date individualized action plans for schools

### What if I cannot access a neuropsychologist?

Barriers such as distance, finances, and provider availability can make it difficult to obtain these appointments for some families. While monitoring MRI scans are essential for asymptomatic males with ALD to enable early detection of cerebral ALD, neuropsychology appointments may be considered a supplemental service when cognitive, developmental, and behavioral concerns are not present.

### What is the role of insurance in these appointments?

Most insurance providers cover neuropsychology appointments, especially if an appropriate referral is placed. Check with your specific insurance and the neuropsychologist you are working with to confirm insurance coverage before your appointment. Because these appointments are longer than a typical doctor's visit, they can cost several thousand dollars without insurance coverage.



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### Where can I access or make neuropsychology appointments?

You will likely need a referral from a primary care physician, neurologist, or other specialist who is caring for you or your child. If a specific neuropsychologist or clinic is not recommended by your referring provider, neuropsychology services can be found in most major hospital settings. Some unique medical centers have neuropsychologists who specialize in rare neurological disorders such as ALD, however this is not common. Most neuropsychologists should be able to understand you or your child's functioning and make recommendations about cognitive and emotional health even if they are not a specialist for ALD.

Because neuropsychology is a specialized field, these professionals tend to be concentrated in urban areas and have long waitlists. If there are no neuropsychologists near you, consider neuropsychologists with telehealth options elsewhere in your state. Often appointments are scheduled months in advance. Remember to check with your insurance about what options you may have for these types of visits.

