

Getting Prepared For Your Initial Visit at an ALS Clinic

It's good to prepare ahead of time for each visit to your ALS clinic. Here are a few questions you may want to ask during your first visit after an ALS diagnosis is confirmed. These questions may be answered over a series of visits.

There is often a lot of information to absorb during a clinic visit. Take a family member or friend with you who can take notes, and ask your care team whether you can record your visit so you can listen to their answers and advice again at a later time.

Provider Name:

Provider Contact Information:

1. Can you tell me about your experience working with ALS patients and families?

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2. How often will I be expected to come to the clinic in person? Do you offer telehealth visits?

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3. How will you explore clinical trials and alternative treatments that may be appropriate for me?

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4. What type of specialists should I expect to meet with during each visit?

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5. How do you work with other specialists?

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6. Can you provide referrals to a satellite clinic or other health providers in my community who are familiar with ALS?

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7. What tests will be used to measure and track the progression of my ALS?

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8. How open are you to designing my care plan based on what my personal values and goals are?

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9. I understand that ALS progresses differently in each person, and you may not be able to tell me exactly what will happen to my body and when. However, it's important to me to feel prepared. Will you share what I can potentially expect to experience?

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10. How do you communicate with patients and how often?

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Write down other questions you have:

- 1.
- 2.
- 3.
- 4.
- 5.

Make a note of who will be on your care team and how you can contact them throughout your experience.

Provider Specialty	Name of Provider	Contact Information & Preferred Method
Neurologist		
Pulmonologist		
Nurse		
Occupational Therapist		
Physical Therapist		
Respiratory Therapist		
Speech & Language Pathologist		
Dietician/Nutritionist		

Other		
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I AM ALS does not provide medical advice. Please discuss questions and decisions related to your diagnosis and medical care with your health care team.

