Questions To Ask Leading up to an ALS Diagnosis

The process leading up to an ALS diagnosis can often be a lengthy one, and includes multiple tests. As there is no test to diagnose ALS, the testing is conducted to rule out other diseases or disorders. As a result, it may take some time before a diagnosis is confirmed. The following questions may be helpful in guiding your discussion with your physician about what to expect during the diagnostic process. 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 with diagnosing ALS?

2. What testing is needed before a diagnosis of ALS can be ruled out or confirmed? What do I need to do to prepare for it? Will any of them hurt?

3. Will you review all my test results with me?

4. How long will testing take before a diagnosis can be made?

5. Is it possible that some tests may be inconclusive? If yes, what is the next step after testing?

6. What other diagnoses fit my symptoms?

7. If I do have ALS, what are treatment options? What can you help me learn about clinical trials for ALS now so I feel more knowledgeable about my options if I am diagnosed with it?

IAM ALS
8. Is there anything I can do now to prevent the progression of ALS?
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   ...

9. If I do have ALS, will you continue to be my doctor? What specialists should be on my health care team?
   ...
   ...

Write down other questions you have:
1.
2.
3.
4.
5.

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.