Patient Information about ALS (Lou Gehrig’s Disease)

Amyotrophic lateral sclerosis, also called ALS or Lou Gehrig’s disease, is a progressive neuromuscular disease. Over time, ALS interferes with the ability to walk, speak, swallow, and breathe, and eventually results in complete paralysis. At this time, there is no cure for ALS.

Lou Gehrig’s disease usually is diagnosed during middle age and affects men more often than women. Although a small percentage of ALS cases are related to an inherited genetic defect, the cause is unknown in a vast majority of cases.

Here are some questions to ask your doctor (e.g., neurologist) about ALS. Print this page, mark the questions you would like to have answered, and bring it with you to your next appointment. The more you know about ALS, the easier it will be to make informed decisions about medical care for yourself or your family member.

Questions to Ask Your Doctor about ALS (Lou Gehrig’s disease)

☐ What are the most common ALS symptoms?

☐ What is leading you to suspect that I might have Lou Gehrig’s disease?

☐ Are Lou Gehrig’s disease symptoms similar to those caused by other conditions or diseases?

☐ What tests will be performed to confirm or rule out amyotrophic lateral sclerosis?

☐ How should I prepare for these tests?

☐ Should I call for the test results or will someone contact me?

Telephone number to call:   Date:  

☐ If these diagnostic tests for ALS are positive, what are the next steps?

☐ What are the causes of Lou Gehrig’s disease?

☐ If I have an inherited form of ALS, should my family members, including children, be tested?

☐ What is the expected prognosis for people with ALS?

☐ What can I expect in terms of quality of life?

☐ Who will be the members of my health care team?
☐ How do I reach these medical professionals?

☐ How will my condition be monitored?

☐ How might ALS symptoms change or progress over time?

☐ Is it possible to slow progression of the disease?

☐ Are there any medications that have proven effective in treating amyotrophic lateral sclerosis symptoms?

☐ What are the common side effects of these drugs?

☐ What should I do if my symptoms worsen, or if I develop new symptoms or severe medication side effects? **Telephone number to call:**

☐ Am I a candidate for physical or occupational therapy? Why or why not?

☐ What other specialized treatments are available?

☐ What research is being done regarding ALS treatments and prevention?

☐ Do you recommend that I participate in a clinical trial for ALS patients? Why or why not?

☐ Can you recommend additional resources for support or information for people with ALS?

☐ Can you recommend additional resources for support or information for my friends, caregivers, and family members?

☐ Next appointment:
  Doctor: 
  Date: 
  Time:

Notes/Additional Information