



## CARE OF ALS: MULTIDISCIPLINARY CARE AND MANAGEMENT OF BEHAVIORAL AND THINKING PROBLEMS

This fact sheet may help you understand the benefits of multidisciplinary care and management of behavioral and thinking problems in people with amyotrophic lateral sclerosis (ALS), sometimes referred to as PALS. For information on managing symptoms and problems with nutrition and breathing in people with ALS, please read the AAN Summary of Evidence-based Guideline for Patients and their Families on *Care of ALS: Drug, Symptom, Nutritional, and Breathing Therapies*.

Neurologists from the American Academy of Neurology are doctors who identify and treat diseases of the brain and nervous system. The following evidence-based information\* is provided by experts who carefully reviewed all available scientific studies on the care of people with ALS.

### What is ALS?

ALS is a disease that affects your ability to control voluntary muscles. It is also known as Lou Gehrig's disease. In ALS, certain nerve cells in the brain and spinal cord become damaged. The affected cells are called motor neurons. These nerve cells send signals to the muscles that you can control, such as the muscles in your arms and legs. The nerves that control automatic actions in the body, such as your heartbeat and digestion, are not affected.

People with ALS lose muscle strength and control. Eventually they are not able to stand or walk, or use their hands and arms; they also have difficulty breathing and swallowing.

The cause of ALS is not yet known, and researchers continue to look for one.

### Is there a cure for ALS? Will I die from it?

ALS is a serious disease. However, it is important to know that several therapies are now available to make daily life easier and more comfortable.

ALS progresses quickly and eventually leads to death. Most people with ALS die within three to five years from the onset of their first symptoms.

However, if you are diagnosed with ALS, you should know that it is possible to live longer and with some relief from symptoms. About 10 percent of people with ALS survive for 10 years or longer. Also, the available treatments can make daily life easier and more comfortable.

### My doctor says my ALS will greatly affect my health and how I live my life. How should I go about getting the care I need?

ALS affects the body in many ways, which leads to necessary changes to your daily routine. Well-organized special clinics designed to care for people with ALS are now available. These clinics are called multidisciplinary clinics because they provide a central location with many services that can help meet the needs of people with ALS. These services include sessions with a neurologist or rehabilitation specialist experienced in treating ALS, as well as a nurse case manager. These people will work to coordinate your care.

You also will meet with several other types of specialists, each of whom will focus on a particular area of care if you eventually need it. A physical therapist will work with you on toning muscles and maintaining range of motion and mobility. He or she also will assist you with choosing devices that help with movement. An occupational therapist will help you and your caregiver with performing daily activities and adapting your home environment to meet your changing needs. A speech pathologist will help you develop different ways of communicating and give advice to make swallowing easier. A dietitian will guide you with nutrition, and a respiratory therapist will help you manage your breathing. A social worker will work with you on how to cope with the disease and will identify additional resources to help you make the needed changes to your daily routine.

There is good evidence that visiting a multidisciplinary clinic can help people with ALS get the best possible care for their condition. Good evidence also shows that people with ALS who visit a multidisciplinary clinic live longer than those who don't. There is weak evidence that people with ALS experience better quality of life by attending a multidisciplinary clinic. Keep in mind that you may need a referral from your primary care doctor to attend such a clinic.

## Is ALS a purely physical disease?

ALS is mainly thought of as a physical disease. Many people with ALS have problems only with voluntary muscles. However, other people with ALS also develop problems with thinking ability or behavior changes, or both. In some cases, the effects on the brain can lead to a form of dementia. The dementia that can occur with ALS progresses slowly and leads to changes in social behavior, loss of the ability to express feelings clearly and appropriately, and loss of the ability to reflect on things deeply. Other problems in this type of dementia are language problems and poor self-care.

Because these problems with thinking ability and behavior changes usually appear slowly, you may not notice them until they have become serious. It is important to try to detect and manage these problems as early as possible. Some people with ALS who develop these types of problems might struggle with starting or continuing important therapies that may prolong their survival or improve their quality of life.

There are tests available that screen for behavioral or thinking problems in people with ALS. Good evidence shows that people with ALS should be screened for possible problems with thinking ability. If you are screened for a problem with thinking ability and the results are positive, your doctor may suggest further testing. Talk to your doctor about whether such tests would be useful for you. Also ask your doctor about therapies that may help you and your caregivers to manage these changes.

This statement is provided as an educational service of the American Academy of Neurology. It is based on an assessment of current scientific and clinical information. It is not intended to include all possible proper methods of care for a particular neurologic problem or all legitimate criteria for choosing to use a specific procedure. Neither is it intended to exclude any reasonable alternative methodologies. The AAN recognizes that specific patient care decisions are the prerogative of the patient and the physician caring for the patient, based on all of the circumstances involved.

\*After the experts review all of the published research studies, they describe the strength of the evidence supporting each recommendation:

*Strong* evidence = more than one high-quality scientific study

*Good* evidence = at least one high-quality scientific study or two or more studies of a lesser quality

*Weak* evidence = the studies, while supportive, are weak in design or strength of the findings

*Not enough* evidence = either different studies have come to conflicting results or there are no studies of reasonable quality

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