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ALS

More than 90 million Americans live with chronic diseases, such as Amyotrophic lateral sclerosis (ALS).

ALS, also called Lou Gehrig's disease, is a progressive, fatal neurological disease affecting as many as 20,000 Americans with 5,000 new cases occurring in the United States each year. The disorder belongs to a class of disorders known as motor neuron diseases. ALS occurs when specific nerve cells in the brain and spinal cord that control voluntary movement gradually degenerate. The loss of these motor neurons causes the muscles under their control to weaken and waste away, leading to paralysis. ALS manifests itself in different ways, depending on which muscles weaken first. Symptoms may include tripping and falling, loss of motor control in hands and arms, difficulty speaking, swallowing and/or breathing, persistent fatigue, and twitching and cramping, sometimes quite severely. ALS strikes in mid-life. Men are about one-and-a-half times more likely to have the disease as women.

There is no cure for ALS, nor is there a proven therapy that will prevent or reverse the course of the disorder. ALS is usually fatal within five years after diagnosis.

Amyotrophic Lateral Sclerosis or Lou Gehrig's Disease

The University of Chicago Hospitals have the longest-running ALS clinic in the world. As a leader in helping people with ALS, the University of Chicago is a core facility for National Institutes of Health research and is participating in the largest multi-center ALS clinical trial to date.

About ALS

Amyotrophic lateral sclerosis is a progressive, fatal neuromuscular disease that attacks nerve cells and pathways in the brain and around the spinal cord. The largest nerve cells — motor neurons — are supposed to send signals from the brain to the spinal cord and then to the muscles. With ALS, motor neurons die and cannot send signals to the muscles; thus, the muscles receive no nourishment and then "atrophy," or waste away. All voluntary muscle actions are affected and the person eventually becomes totally paralyzed. The mind, however, is not affected so the person retains cognitive function despite the total degeneration of the body.

Symptoms

Symptoms of this neurodegenerative disease typically begin between the ages of 40 and 70, although some people develop ALS as young as their 20s or 30s. Early symptoms may include loss of coordination (tripping, dropping items), fatigue in the arms or legs, muscle cramps or twitches, slurred speech, or uncontrollable spells of laughing or crying. Degeneration usually starts in the hands and feet, progresses to the arms and legs, and eventually reaches the trunk to impair swallowing, chewing and breathing functions.

Diagnosis

ALS is difficult to diagnose because early symptoms can mimic other conditions. The University of Chicago Hospitals have state-of-the-art neurophysiology resources to conduct tests to identify ALS, including electromyography. Neurologists her, with their expertise in neuroimmunology, are able to distinguish ALS from neuroimmunologic syndromes which may look like ALS.

Treatment

Patients receive care from specialists in the long-established MDA/ALS clinic at the University of Chicago Hospitals.

Current medical science lacks the tools to slow the progression of ALS or restore lost motor neurons and atrophied muscles. Until recently, there was no real treatment for ALS and therapy was aimed only at relieving pain, relaxing muscle cramps or easing other symptoms and complications. The FDA recently

approved the first drug, riluzole, which may slow the degeneration for some people with ALS. This drug and other innovative therapies are available to patients at the University of Chicago Hospitals. Thanks to research and improved medical care, ALS patients are living longer and remaining productive for more years after the onset of symptoms.

U of C Research in ALS

Research is directed toward better understanding of the pathogenesis of neurodegenerative diseases such as ALS. Physician researchers at the University of Chicago have a large NIH-funded ALS research "program project" grant. Projects in this large grant include studies of:

- Genes that may cause ALS-like syndromes when mutated
- Genetic animal models of ALS
- Mechanisms involved in the death of motor neurons and their rescue.

TREATMENT FOR ALS

Currently there is no cure for ALS, yet patients suffering from the disease can be made more comfortable with the following options:

- medications to relieve painful muscle cramps, excessive salivation and other symptoms.
- heat or whirlpool therapy to relieve muscle cramping.
- exercise, although recommended in moderation, may help maintain muscle strength and function.
  physical therapy to maintain mobility and ease the discomfort of muscle stiffness, cramps and fluid retention.
- nutritional counseling to promote good nutrition and offer other dietary options when swallowing becomes difficult.
- speech therapy and communication training to maintain as many verbal communication skills as possible. Communication training also indicates non-verbal techniques.
- devices such as splints, corrective braces, grab bars, reach-extenders, etc. to help with daily activities such as dressing, eating, using the toilet and bathing.
- special equipment such as wheelchairs, electric beds or mattresses to maximize functional independence.

Recently the US Food and Drug Administration (FDA) approved Rilutek®, the first drug that has reliably prolonged the survival of persons with ALS. Patients, however, will not get stronger nor regain lost strength with this drug.

Managing the symptoms is a process that may be challenging for people with ALS, their care givers and the medical team, but there are many community resources available for support and assistance.

HOW IS ALS DIAGNOSED?

In addition to a complete medical history and physical examination, diagnostic procedures for ALS may include:

- laboratory tests - including blood and urine studies and thyroid functioning tests
- muscle and/or nerve biopsy
- cerebral spinal fluid analysis (spinal tap) -- a procedure used to make an evaluation or diagnosis by examining the fluid withdrawn from the spinal column.
- X-rays
- magnetic resonance imaging (MRI) - a way to image soft tissues that's noninvasive and that doesn't involve X-rays. MRI produces a sharp, two-dimensional view of the brain and spinal cord.
- electrodiagnostic tests (i.e., electromyography (EMG) and nerve conduction velocity, or NCV) - studies that evaluate and diagnose disorders of the muscles and motor neurons. Electrodes are inserted into the muscle, or placed on the skin overlying a muscle or muscle group, and electrical activity and muscle response are recorded.

CAUSES OF ALS -- WHAT WE'RE LOOKING FOR

As described here, ALS is a somewhat diverse and decidedly mystifying disease. In more than nine out of every 10 cases diagnosed, no clear identifying cause of the disease is apparent, that is, patients lack an obvious genetic history, complete with affected family members. Also, nothing about the way patients live their lives gives scientists and clinicians clues as to what causes ALS. Nothing in patients' diet, where they've lived, how they've lived or what they've done with their lives can easily explain why they've developed this late onset, fully developed and progressive disease.

However, in about 5 percent of cases, a clear genetic history exists. The disease is classed as autosomal dominant in these patients; that is, that almost half of all family members show a clear history of ALS. Studies in the early 1990s on the genetic form of the disease, including work by one of our scientific advisors, Dr. Robert Brown, revealed that a single gene defect could account for a portion of these familial cases.

Mutations in the gene for the enzymes superoxide dismutase 1 (SOD1) or copper zinc superoxide dismutase have been found in approximately 15-20 percent of the familial cases of ALS. Some quick math shows, then, that approximately 1 to 2 percent of all cases of ALS involve this particular gene mutation.

Still, for the majority of ALS cases, we do not know what causes the disease. Researchers haven't been idle, however, and several attractive theories exist on what could cause or contribute to the death of motor neurons in ALS. Center scientists are focusing on these pathogenic theories.

GLOSSARY OF TERMS

A

acetylcholine - a chemical in the brain that acts as a neurotransmitter.

action tremor - a tremor that increases when the hand is moving voluntarily.

activities of daily living (ADLs) - personal care activities necessary for everyday living, such as eating, bathing, grooming, dressing, and using the toilet; a term often used by healthcare professionals to assess the need and/or type of care a person may require.

advance directives - documents (such as a Living Will) completed and signed by a person who is legally competent to explain wishes for medical care should he or she become unable to make those decisions at a later time.

agitation - a non-specific symptom of one or more physical, or psychological processes in which screaming, shouting, complaining, moaning, cursing, pacing, fidgeting or wandering pose risk or discomfort, become disruptive or unsafe or interfere with the delivery of care.

agonist - a drug that increases neurotransmitter activity by directly stimulating the nerve cell receptors.

akinesia - no movement.

ataxia - loss of balance.

Alzheimer's disease - A progressive, degenerative brain disease that results in impaired memory, thinking, and behavior.

amyotrophic lateral sclerosis (ALS) - a terminal neurological disorder characterized by progressive degeneration of motor cells in the spinal cord and brain. It is often referred to as "Lou Gehrig's disease."

arteriogram (angiogram) - an X-ray scan of arteries going to and through the brain. Patients who have arteriograms first are injected with a radiopaque dye.

athetosis - slow, involuntary movements of the hands and feet.

atrophy - wasting and shrinkage of tissue.

axon - the long, hairlike extension of a nerve cell that carries a message to the next nerve cell.

B

basal ganglia - several large clusters of nerve cells, including the striatum and the substantia nigra, deep in the brain below the cerebral hemispheres.

Bell's palsy - An unexplained episode of facial muscle weakness or paralysis that begins suddenly and steadily worsens.

blink rate - the number of times per minute that the eyelid automatically closes -- normally 10 to 30 per minute.

blood-brain barrier - the protective membrane that separates circulating blood from brain cells.

bradykinesia - slowness of movement.

bradyphrenia - slowness of thought processes.

brain attack - another term for stroke.

brisk reflex - a condition that describes the deterioration of the upper motor nerve cells (neurons).

bulbar muscles - the muscles that control the speech, chewing and swallowing.

C

central nervous system - the brain and the spinal cord.

cerebral embolism - a situation in which a wandering clot (embolus) or some other particle lodges in a blood vessel in the brain.

cerebral hemorrhage - a type of stroke occurs when a defective artery in the brain bursts, flooding the surrounding tissue with blood

cerebral thrombosis - the most common type of brain attack, it occurs when a blood clot (thrombus) forms and blocks blood flow in an artery bringing blood to part of the brain.

cerebellum - a large, two-halved structure (hemispheres) located in the lower part of the brain that's responsible for the coordination of movement and balance.

cerebrospinal fluid analysis (spinal tap) - the withdrawing and examination of a small sample of the fluid that bathes the spinal cord.

cerebrum - the two largest, most complex and most developed lobes of the brain. Initiation and coordination of all voluntary movement take place within the cerebrum. The basal ganglia are located immediately below the cerebrum.
chorea - rapid, jerky, dance-like movement of the body.

classical ALS - a progressive neurological disease characterized by a deterioration of upper and lower motor nerve cells (neurons). This type of ALS affects more than two-thirds of all people with ALS.

computed tomography (CT or CAT scan) - a non-invasive X-ray procedure that takes cross-sectional images of the brain or other internal organs. It detects abnormalities that may not show up on an ordinary x-ray.

cortex - the outer layer of the cerebrum, densely packed with nerve cells.

cryothalamotomy - a surgical procedure in which a supercooled probe is inserted into a part of the brain called the thalamus in order to stop tremors.

D

delusions - a condition in which the patient has lost touch with reality and experiences hallucinations and misperceptions.

dementia - not a disease itself, but a group of symptoms that characterize diseases and conditions. Dementia commonly is defined as a decline in intellectual functioning severe enough to interfere with the ability to perform routine activities.

dendrite - a threadlike extension from a nerve cell that acts like an antenna, receiving messages from the axons of other nerve cells.

dopa decarboxylase - an enzyme present in the body that converts levodopa to dopamine.

dopamine - a chemical substance, a neurotransmitter, found in the brain that regulates movement, balance, and walking.

dysarthria - impaired speech and language due to weakness or stiffness in the muscles used for speaking.

dyskinesia - an involuntary movement including athetosis and chorea.

dysphagia - difficulty in swallowing.

dystonia - a slow movement or extended spasm in a group of muscles.

dystrophin - a protein, a chemical substance made by muscle fibers.

E

electrodiagnostic tests – studies including **electromyography (EMG)** and **nerve conduction velocity (NCV)**, that evaluate and diagnose disorders of the muscles and motor neurons. Electrodes are inserted into the muscle, or placed on the skin overlying a muscle or muscle group, and electrical activity and muscle response are recorded.

electroencephalogram (EEG) - a method of recording the brain's continuous electrical activity by means of electrodes attached to the scalp.

embolus - a "wandering" blood clot.
encephalitis - an infection of the brain.

epilepsy - a brain disorder involving recurrent seizures; may also be called a seizure disorder.

euphoria - a feeling of well-being or elation; may be drug related.

evoked potentials - a procedure to record the brain's electrical response to visual, auditory and sensory stimuli.

exertional dyspnea - a condition characterized by shortness of breath during physical activity.

extensor muscle - any muscle that causes the straightening of a limb or other part.

extrapyramidal system (EPS) - the nerve cells, nerve tracts and pathways that connect the cerebral cortex, basal ganglia, thalamus, cerebellum, reticular formation, and spinal neurons. The EPS helps regulate reflex movements such as balance and walking.

F

familial ALS - a progressive neurological disease that affects more than one member of the same family. This type of ALS accounts for a very small number of people with ALS in the United States (5 to 10 percent).

fasciculations - non-painful, rapid and involuntary contractions or twitchings of groups of muscle fibers. This is often described by people with ALS as "persistent rolling beneath the skin."

festination - walking with a series of quick, small, shuffling steps as if hurrying forward to keep balance.

flaccid muscles (also hypotonicity) - a condition characterized by a decrease or loss of normal muscle tone due to the deterioration of the lower motor nerve cells.

flexor muscle - any muscle that causes the bending of a limb or other body part.

G

ganglion - a cluster of nerve cell bodies.

gray matter - the darker-colored tissues of the central nervous system; in the brain, the gray matter includes the cerebral cortex, the thalamus, the basal ganglia, and the outer layers of the cerebellum.

Guillain-Barre syndrome - A disorder in which the body's immune system attacks part of the nervous system.

H

headache-primary - includes tension (muscular contraction), vascular (migraine), and cluster headaches not caused by other underlying medical conditions.

headache-secondary - includes headaches that result from other medical conditions. These may also be referred to as traction headaches or inflammatory headaches.

hyperreflexia - excessive response of muscle reflexes when a normal stimulus is applied.

hyporeflexia - weak or absent muscle response when a normal stimulus is applied.

I

incontinence - involuntary voiding of the bladder or bowel.

J

K

L

levodopa (L-dopa) - the single most effective anti-Parkinson drug, it is changed into dopamine in the brain.

Lewy body - A pink-staining sphere, found in the bodies of dying cells and thought to be a marker for Parkinson's disease.

lordosis - an exaggeration of the forward curve of the lower part of the back, sometimes called sway-back.

lower motor neurons - nerve cells (neurons) starting at the spinal cord or brain stem and ending at the muscle fibers.

M

magnetic resonance imaging (MRI) - a non-invasive, non-X-ray procedure that produces two-dimensional view of an internal organ or structure. MRI is especially useful for imaging the soft tissues of the brain and spinal cord.

meningitis - an inflammation of the meninges, the membranes that cover the brain.

micrographia - a change in handwriting with the script becoming smaller and more cramped.

monoamine oxidase (MAO) - an enzyme that breaks down dopamine. MAO comes in two forms: A and B. In Parkinson's disease, it is beneficial to block the activity of MAO B.

motor neuron diseases - a group of disorders in which motor nerve cells (neurons) in the spinal cord and brain stem deteriorate and die. ALS is the most common motor neuron disease.

multiple sclerosis (MS) - a disease of the central nervous system that is unpredictable. MS can be relatively benign, disabling, or devastating, leaving the patient unable to speak, walk, or write.

muscle cramps, unexpected - involuntary, painful shortening of muscles. Usually, a knotting of the muscles is visible.

muscle weakness - loss of muscle strength with increased fatigue, loss of coordination, difficulty with motor skills and lack of ability to carry out certain other skills.

muscular dystrophy - the name given to a group of diseases that are, for the most part, genetically determined and which cause gradual wasting of muscle with accompanying weakness and deformity.

myelogram - a procedure that uses dye injected into the spinal canal to make the structure clearly visible on x-rays.

myoclonus - jerking, involuntary movements of the arms and legs. May occur normally during sleep.

N

neuron - a cell specialized to conduct and generate electrical impulses and to carry information from one part of the brain to another.

neurosonography - a procedure that uses ultra high frequency sound waves to reveal patterns of blood flow. It is commonly used to help confirm stroke.

neurotransmitters - chemical substances that carry impulses from one nerve cell to another; found in the space (synapse) that separates the transmitting neuron's terminal (axon) from the receiving neuron's terminal (dendrite).

nigral - of or referring to the substantia nigra.

norepinephrine - a neurotransmitter found mainly in areas of the brain involved in governing autonomic nervous system activity, especially blood pressure and heart rate.

O

on-off effect, on-off phenomena - a change in the patient's condition, with sometimes rapid fluctuations between uncontrolled movements and normal movement, usually occurring after long-term use of levodopa and probably caused by changes in the ability to respond to this drug.

orthostatic hypotension - a large decrease in blood pressure upon standing; may result in fainting.

P

pallidotomy - a surgical procedure in which a part of the brain called the globus pallidus is lesioned in order to improve symptoms of tremor, rigidity, and bradykinesia.

parkinsonism - the name given to a group of disorders with similar features -- four primary symptoms (tremor, rigidity, postural instability, and bradykinesia) that are the result of the loss of dopamine-producing brain cells.

Parkinson's disease (PD, Parkinson's) - The most common form of parkinsonism, is a slowly progressing, degenerative disease that is usually associated with the following symptoms all of which result from the loss of dopamine-producing brain cells: tremor or trembling of the arms, jaw, legs, and face; stiffness or rigidity of the limbs and trunk; bradykinesia -- slowness of movement; postural instability, or impaired balance and coordination.

palsy - paralysis of a muscle or group of muscles.

peristalsis - wavelike contractions that move food through the digestive tract.

positron emission tomography (PET) scan - a computer-based imaging technique that provides a picture of the brain's activity rather than its structure. The technique detects levels of injected glucose labeled with a radioactive tracer.

primary lateral sclerosis (PLS) - a progressive neurological disease in which the upper motor nerve cells (neurons) deteriorate. If the lower motor neurons are not affected within two years, the disease usually remains a pure upper motor neuron disease. This is the rarest of all forms of ALS.

progressive bulbar palsy (PBP) - a condition that begins with difficulties in speaking, chewing and swallowing due to lower motor nerve cell (neuron) deterioration. This disorder affects about 25 percent of all people with ALS.

progressive muscular atrophy (PMA) - a progressiveneurological disease in which the lower motor nerve cells (neurons) deteriorate. If the upper motor neurons are unaffected within two years, the disease usually remains a pure lower motor neuron disease.

pseudobulbar palsy - a condition characterized by difficulties with speech, chewing and swallowing. These symptoms resemble those of bulbar palsy, but this condition is also characterized by spontaneous or unmotivated crying and laughing.

pyramidal pathway - a collection of nerve tracts that travel from the cerebral cortex through the pyramid of the medulla oblongata in the brainstem to the spinal cord. Within the pyramid of the medulla, fibers cross from one side of the brain to the opposite side of the spinal cord; the pyramidal pathway is intact in Parkinson's disease.

Q

R

range of motion - the extent that a joint will move from full extension to full flexion.

resting tremor - a tremor, in a limb, that increases when the limb is at rest.

retropulsion - the tendency to step backwards if bumped from the front or upon initiating walking, usually seen in patients who tend to lean backwards because of problems with balance.

rigidity - increased resistance to the passive movement of a limb.

S

serotonin - a chemical necessary for communication between nerve cells.

sialorrhea - drooling.

somatostatin - a chemical necessary for communication between nerve cells.

spasm - a condition in which a muscle or group of muscles involuntarily contract.

spinal muscular atrophy (SMA) - a hereditary neurological disease in which only the lower motor nerve cells are affected.

striatum - part of the basal ganglia, it is a large cluster of nerve cells, consisting of the caudate nucleus and the putamen, that controls movement, balance, and walking; the neurons of the striatum require dopamine to function.

stroke - also called a "brain attack" - a cluster of symptoms that appear suddenly when brain cells die because of inadequate blood flow.

subarachnoid hemorrhage - a brain attack that occurs when a blood vessel on the surface of the brain ruptures and bleeds into the space between the brain and the skull (but not into the brain itself).

substantia nigra - a small cluster of black-pigmented nerve cells in the brain that produce dopamine. Messages from the substantia nigra are transmitted to the striatum.

sustention (postural) tremor - a limb tremor that increases when the limb is stretched.

synapse - a tiny gap between the ends of one nerve cell and the beginning of another. Impulses pass from one nerve cell to another at the synapse. Impulses traveling down one nerve cell cause the release of a neurotransmitter which diffuses across the gap and triggers an electrical impulse in the next neuron.

T

thrombus - a blood clot.

tremor - a rhythmical shaking of a limb, head, mouth, tongue, or other part of the body.

tyrosine - the amino acid from which dopamine is made.

U

upper motor neurons - nerve cells (neurons) originating in the brain's motor cortex and running through the spinal cord.

V

W

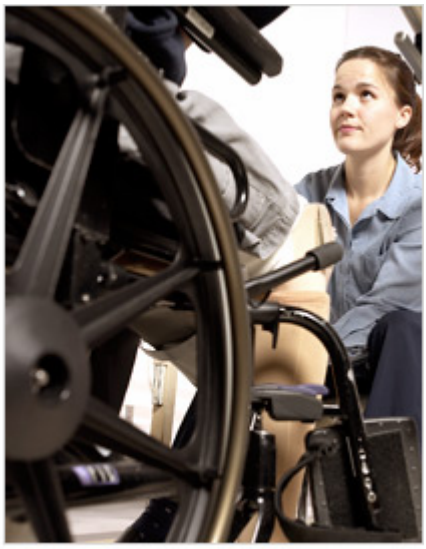
white matter - nerve tissue that is paler in color than gray matter because it contains nerve fibers with large amounts of insulating material (myelin). The white matter does not contain nerve cells. In the brain, the white matter lies within the gray layer of the cerebral cortex.

X

Y

Z

Amyotrophic Lateral Sclerosis (ALS)



Signs and Symptoms

Take a moment, and point at the computer screen. Notice that your index finger is extended and your other fingers are curled into your palm.

How did your hand know to do that?

It all began in your brain, the starting point for an important chain of communication. Your brain ordered nerve cells, called motor neurons, to activate muscles in your hand and fingers. In this instance, your muscles responded, and your fingers moved.

In a person afflicted with Amyotrophic Lateral Sclerosis (ALS), there is a break in the chain of communication. The motor neurons degenerate and die. Because of the lack of motor neurons, the brain cannot communicate with the muscles, and voluntary muscle movement is no longer possible. Because the muscles are no longer used, they too begin to degenerate and weaken causing a wide range of disabilities.

ALS progresses rapidly and leads to paralysis. Often, the degenerating muscles in the chest and diaphragm cause a person with ALS to rely on mechanical ventilation for breathing, and most sufferers die of respiratory failure within three to five years from the onset of symptoms. Some sufferers have survived more than 10 years. Stephen Hawking, a world famous physicist, has lived with ALS for nearly 40 years. He was diagnosed with the disease at age 21. Since then, he has married, fathered three children, and written numerous books with the help of a special computer.

It is important to remember that a person suffering with ALS has normal brain function, as is clearly demonstrated in Stephen Hawking. The person can think clearly, remember things, and have the same level of intelligence as before the ALS diagnosis was made. ALS affects the chain of communication at the motor neuron level. So, the brain is not affected.

ALS does NOT affect:

- Mind (memory, intelligence)
- Personality
- Vision
- Sense of smell
- Taste

- Hearing
- Ability to recognize touch
- Bladder or bowel functions (typically)

ALS does affect:

- Speech
- Swallowing
- Chewing
- Breathing

ALS is sometimes referred to as Motor Neuron Disease or Lou Gehrig's disease for Lou Gehrig, the famed baseball player for the New York Yankees, who became afflicted with ALS, eventually dying from the disease in 1941.

ALS is a rare disease. Only two out of every 100,000 people will become afflicted. That means that there are approximately 5,000 new cases of ALS in the United States each year.

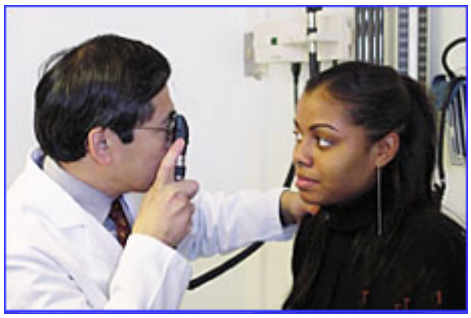
In rare cases, ALS may be inherited. This inherited form of ALS is called Familial ALS, but only 5 to 10% of cases are inherited. The most common type of ALS is Sporadic ALS. It can strike anyone regardless of race, ethnic background, or even age. Children can get ALS, but it is extremely rare. The most common age for a person to first notice symptoms is between the ages of 40 to 70 years old.

Signs and Symptoms

ALS typically starts in one part of the body, like the hands, feet, or limbs. You may notice that you are dropping things, have slurred speech, or difficulty walking. You may find that you have difficulty buttoning your clothes, that you are experiencing muscle cramps, or that you feel twitching in your arms, shoulders, or tongue. You will probably feel very fatigued, but it is important to remember that the disease progresses differently in everyone.

These symptoms are also the symptoms for other conditions, like stroke or Parkinson's disease, so before coming to your own conclusions, it is important to see your health care professional for an accurate diagnosis.

Diagnosing ALS



At the Eleanor and Lou Gehrig MDA/ALS Multidisciplinary Care Center, a neurologist with expertise in ALS conducts the ALS evaluation. The first step in being evaluated is to be seen by Dr. Mitsumoto or one of his associates at the Center. A thorough neurological examination will be conducted and previous tests reviewed. If indicated, additional diagnostic examinations (tests) may be recommended.

On the day of the evaluation with the neurologist, you may also be seen by one of the ALS nurse clinicians. The nurse clinician will assist you with additional information you may need regarding the evaluation and tests recommended, prescriptions, and, if indicated, referrals for physical rehabilitation. In this way your symptoms may be addressed even in the absence of a definite diagnosis.

You will be asked to return to the ALS Multidisciplinary Care Center after all of your testing is complete to meet again with the neurologist for a diagnostic discussion. If the diagnosis is confirmed, you will also meet with the multidisciplinary team members who will provide evaluation and specific recommendations for how to approach the changes you are experiencing.

It is very important that the individual diagnosed with ALS maintain regular contact with an ALS center. Effective symptom management will help maintain and enhance quality of life. This includes regular assessment of physical functioning in order to provide education and guidance concerning the maintenance of strength, balance, and safety. Additionally, nutritional intake should be assessed regularly and adjustments made according to changes in physical status. Respiratory function should also be monitored on a regular basis.

Symptoms such as muscle cramps and stiffness and excess saliva can often be alleviated with medications. Adaptive and augmentative equipment can help to maintain effective communication, mobility, and safety.

It is also extremely important that the individual diagnosed with ALS become educated in order to pro-actively plan their medical care. Long-term prognosis and quality of life is enhanced when individuals participate actively in their medical management. Furthermore, the diagnosis of a chronic long-term illness can be a motivating factor in setting one's affairs in order.

Attending ALS support groups on a regular basis is an effective way to remain abreast of new medical developments.

Additionally, clinical therapeutic research trials should be investigated. The numbers of clinical research trials have risen in the past few years. More therapeutic opportunities are available now than ever before for those diagnosed with ALS.

The multidisciplinary team at the Eleanor and Lou Gehrig MDA/ALS Multidisciplinary Care Center offers expertise, education, resources, and guidance to the individual diagnosed with ALS.

ALS - Lou Gehrig's Disease

"Finding just one doctor who specializes in ALS is difficult enough, finding a whole team with ALS experience like the Center at UCSD can make all the difference in the world to a family battling this disease. I only wish that my dad had the chance to go to a place like this." -- Lori Butler, Chapter President, The ALS Association Greater San Diego Chapter

Amyotrophic lateral sclerosis (ALS), often referred to as "Lou Gehrig's disease," is a progressive neurodegenerative disease that affects nerve cells in the brain and the spinal cord. The degeneration of the motor neurons in ALS eventually leads to muscle weakness and atrophy. Patients in the later stages of the disease may become totally paralyzed, but for the vast majority living with ALS, their minds remain unaffected.

Despite the serious nature of ALS, there are some people who live with ALS for many years -- even decades -- with a high quality of life. Some people have a form of ALS that is very slowly progressive, while others have ALS that requires more immediate medical therapy to help them maintain their mobility, nutritional needs and breathing.

Under the co-directorship of Nayan P. Desai, M.D., and Geoffrey L. Sheean, M.D., the ALS Center at UCSD Medical Center provides expertise and a sensitive approach to caring for individuals with this degenerative disease. Our clinical faculty is complemented by a group of internationally recognized scientists who are working to identify ways to treat, and eventually, prevent ALS from occurring.

If you are living with limited mobility, the convenience of having multiple medical and social services in one place is a blessing. Patients have same-day access to physicians, as well as to physical and occupational therapists, a speech pathologist, a social worker and a nutritionist. Along with our very strong collaboration with ALS researchers, this level of comprehensive care at a single facility makes the UCSD ALS Center unique in Southern California. Soon, our patients will also be able to participate in the latest clinical trials.

Appointments are available the second and fourth Tuesday of the month from 1 p.m. to 4 p.m.

To schedule an appointment, call (619) 543-5300.

ALS Center
200 West Arbor Drive
San Diego, CA 92103
(619) 543-5300

Information for Veterans Who Served in Vietnam

GENERAL INFORMATION

Environmental Agents Service

Department of Veterans Affairs

JULY 2003

Agent Orange was used in Vietnam to protect U.S. troops.

Agent Orange was a herbicide used in Vietnam to kill unwanted plants and to remove leaves from trees that otherwise provided cover for the enemy. The name, "Agent Orange," came from the orange stripe on the 55-gallon drums in which it was stored. Other herbicides, including Agent White and Agent Blue, were also used in Vietnam to a much lesser extent.

When and where Agent Orange was used in Vietnam.

Between 1961 and 1971, the U.S. military in South Vietnam used more than 19 million gallons of herbicides for defoliation and crop destruction. Several types and combinations of chemicals were used. These mixtures were identified by the color of the stripe on the storage drums. The three most common mixtures were Agent Orange, Agent White, and Agent Blue. Fifteen different herbicides were shipped to and used in Vietnam. Most of the herbicides sprayed in Vietnam were Agent Orange, which was used between January 1965 and April 1970. Herbicides other than Agent Orange were used in Vietnam prior to 1965, but to a very limited extent. The total area sprayed with herbicides between 1962 and 1965 was quite small. However, some of the herbicides used in the early years contained greater concentrations of dioxin. Spraying occurred in all 4 military zones of Vietnam.

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Some Vietnam veterans are concerned about the long-term effects of exposure to Agent Orange.

In the 1970's some veterans became concerned that exposure to Agent Orange caused health problems. One of the chemicals in Agent Orange contained minute traces of TCDD (dioxin),

which caused a variety of illnesses in laboratory animals. More recent studies have suggested that the chemical may be related to a number of cancers and other health problems.

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In 1978, the Veterans Administration, now known as the Department of Veterans Affairs (VA), set up the Agent Orange Registry health examination program for Vietnam veterans concerned with the possible long-term medical effects of exposure to Agent Orange. Vietnam veterans who are interested in participating in this program should contact the nearest VA medical center for an examination. More than 315,000 Vietnam Veterans have completed this examination.

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In its 1994 report on Agent Orange, the National Academy of Sciences (NAS) concluded that individual TCDD levels in Vietnam veterans usually are not meaningful because of background exposures to TCDD in all Americans, poorly understood variations among individuals in TCDD metabolism, relatively large measurement errors, and exposure to herbicides that did not contain TCDD.

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The veteran is informed of the results of the examination during a personal interview and gets a follow-up letter further describing the findings. Each veteran is given the opportunity to ask for an explanation and advice. Sometimes a follow-up examination or additional laboratory tests are scheduled because of the possibility of previously undetected medical problems being present. These discoveries can help veterans get prompt treatment for their illnesses. Some veterans think they are in good health, but are worried that exposure to Agent Orange and other substances may have caused some hidden illnesses. The knowledge that a complete medical examination does not show any problems can be reassuring or helpful to Registry participants. All examination and test results are kept in the veteran's permanent medical record. These data are entered into the VA Agent Orange Registry.

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Under Section 102, Public Law 104-262, the Veterans' Health Care Eligibility Reform Act of 1996, VA shall furnish hospital care, medical services and may furnish nursing home care to veterans exposed to herbicides in Vietnam. These veterans will be furnished health care and without the requirement of a copayment. There are some restrictions. VA cannot provide such care for a (1) disability which VA determines did not result from exposure to Agent Orange, or (2) disease which the NAS has determined that there is "limited/suggestive" evidence of no association between occurrence of the disease and exposure to a herbicide agent.

Some Vietnam veterans get disability compensation for Agent Orange-related illnesses.

VA pays disability compensation to Vietnam veterans with injuries or illnesses incurred in or aggravated by their military service. Veterans do not have to prove that Agent Orange caused their medical problems to be eligible for compensation. Rather, VA must determine that the disability is "service-connected." A Veterans Services Representative, at a VA medical center or regional office, can explain the compensation program in greater detail and assist veterans who need help in applying. For more information about the VA's Agent Orange program call

the toll-free helpline: 1-800-749-8387; for disability compensation program information, call toll-free: 1-800-827-1000.

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Other VA efforts are underway to help Vietnam veterans who were exposed to Agent Orange.

In addition to the efforts described above (that is, Agent Orange Registry examination program, medical treatment, and disability compensation), VA is doing research to learn more about the possible adverse health effects of military service in Vietnam. The Environmental Epidemiology Service (EES) is the premiere office for Vietnam/Agent Orange-related research within VA. EES investigators have completed numerous studies on this subject; summaries are available at our website: www.va.gov/agentorange/.

What other government departments and agencies are doing.

Many other Federal departments and agencies have pursued and/or are conducting scientific studies on this subject. The Centers for Disease Control and Prevention (CDC), Air Force

(USAF), National Institute for Occupational Safety and Health (NIOSH), National Cancer Institute

(NCI), and Environmental Protection Agency (EPA) have all been involved in research.

In 1984, the CDC published an important study, partially funded by VA, regarding Vietnam

veterans' risks of fathering babies with birth defects. VA also funded the CDC Vietnam Experience

Study published in 1987 and 1988, and the CDC Selected Cancers Study published in 1990.

For additional information about the CDC effort, see www.cdc.gov/mmwr/mmwrpvol.html for

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Several states have undertaken research efforts to learn more about the possible health effects of Agent Orange and the Vietnam experience upon our Nation's veterans.

The National Academy of Sciences' Institute of Medicine has a major role in this

issue.

Under Public Law 102-4, the Agent Orange Act of 1991, the Institute of Medicine (IOM) of National

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all relevant scientific literature and to provide advice to the Secretary of Veterans Affairs on health

effects of herbicides exposure. The IOM project is being undertaken in accordance with Public Law 102-4. The IOM reported its initial findings in July 1993. Updates were released in March 1996, February 1999, April 2001, and January 2003. A special report on type 2 diabetes was released in October 2000. A special report on acute myelogenous leukemia in the children of Vietnam veterans was issued in February 2002. Future reports are anticipated approximately every two years. The IOM and its subcontractor also developed a historical herbicide exposure reconstruction model that could be used in Agent Orange-related research efforts. For additional information and a complete version of the IOM reports, see www.nap.edu.

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In March 2001, Secretary Principi ordered that those examinations be made available to all other veterans who may have been exposed to dioxin or other toxic substances in a herbicide or defoliant during the conduct of or as the result of testing, transporting, or spraying of herbicides for military purposes.

Additional information is available.

There is at each VA medical center an "Environmental Health Clinician" responsible for the conduct of Agent Orange Registry exams. These health care providers participate in national conference calls conducted by the Environmental Agents Service (EAS), and receive frequent mailings from VA headquarters updating them on the latest developments on Agent Orange issues. Each facility also has an "Environmental Health Coordinator" to facilitate the Agent Orange program.

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Environmental Agents Service

Department of Veterans Affairs

810 Vermont Avenue, NW

Washington, DC 20420

July 2003

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Environmental Agents Service

Department of Veterans Affairs

JULY 2003

Agent Orange was used in Vietnam to protect U.S. troops.

Agent Orange was a herbicide used in Vietnam to kill unwanted plants and to remove leaves from trees that otherwise provided cover for the enemy. The name, "Agent Orange," came from the orange stripe on the 55-gallon drums in which it was stored. Other herbicides, including Agent White and Agent Blue, were also used in Vietnam to a much lesser extent.

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of herbicides for defoliation and crop destruction. Several types and combinations of chemicals were used. These mixtures were identified by the color of the stripe on the storage drums. The three most common mixtures were Agent Orange, Agent White, and Agent Blue. Fifteen different herbicides were shipped to and used in Vietnam. Most of the herbicides sprayed in Vietnam were Agent Orange, which was used between January 1965 and April 1970. Herbicides other than Agent Orange were used in Vietnam prior to 1965, but to a very limited extent. The total area sprayed with herbicides between 1962 and 1965 was quite small. However, some of the herbicides used in the early years contained greater concentrations of dioxin. Spraying occurred in all 4 military zones of Vietnam.

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