



St. Louis Regional Chapter

PROVIDING HEALTH, HELP, AND HOPE

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Proud member of

United Way
of Greater St. Louis



THE ALS ASSOCIATION ST. LOUIS REGIONAL CHAPTER

The ALS Association, St. Louis Regional Chapter is dedicated to improving the quality of life for those affected by Amyotrophic Lateral Sclerosis, educating the community, and supporting research.

The ALS Association is a not-for-profit voluntary health organization dedicated solely to the fight against amyotrophic lateral sclerosis.

Chapter Overview

- **The St. Louis Regional Chapter serves ALS patients and families in Eastern Missouri as well as Central and Southern Illinois.**
- **All services are provided at no cost to the ALS patient and their families.**
- **The chapter is also a resource for information about ALS and the management of ALS for the medical profession, the biotech community, and the media.**

Amyotrophic Lateral Sclerosis

Medical description

- **Amyotrophic Lateral Sclerosis (ALS) is a fatal, neurodegenerative disease.**
- **Often known as Lou Gehrig's disease or motor neuron disease, it is a progressive disorder that occurs when motor nerve cells in the nervous system cease functioning and die.**
- **Muscle control becomes completely lost, resulting in paralysis.**
- **Death normally occurs due to secondary infection or insufficient ability to expel carbon dioxide.**

Lay person's description

- **Motor neurons carry the message from our brain and spinal cord to our muscles in order for us to perform any movement.**
- **In ALS, the motor neurons die and the message is not given to the muscles for movement.**
- **You may want to comb your hair or take a step, but your muscles do not get the message and movement thus becomes difficult and eventually not possible.**
- **Most of the time a person's mental capabilities are not affected.**
- **ALS does not affect the senses.**

Types and Forms

Types of onset

Limb onset

Begins in legs or arms and “spreads” thus affecting all limbs before moving to the bulbar region.

Bulbar onset

Begins in the bulbar region, (located in the brain stem at the base of the head), with speaking and swallowing difficulties. ALS will then move to the limbs.

Forms

- **Sporadic**
 - Most common form.
 - 90% of all cases do not have a genetic predisposition.
- **Familial**
 - Up to ten percent of ALS cases are familial.
 - One form linked to chromosome 21 – SOD1 gene.

Frontotemporal Lobe Dementia (a change in personality and in mental processes), can occur together with ALS.

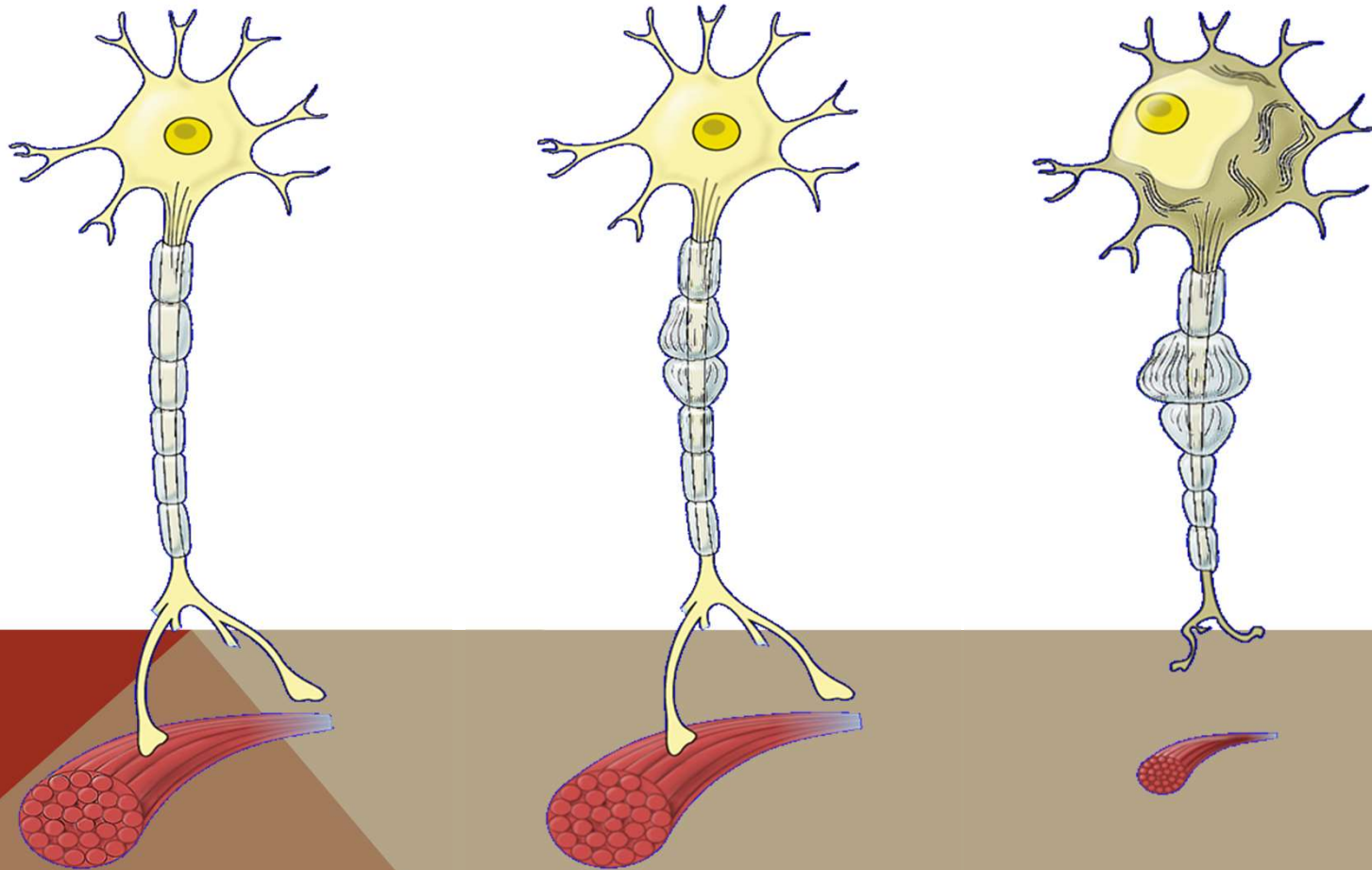
Who is affected by ALS?

- **30,000 Americans at any given time**
- **One person dies from ALS every 90 minutes**
- **Age of onset is most common between the ages of 40 and 70, with the peak age about 55**
- **ALS can strike anyone without regard to race, sex, or socio-economic group**
- **Studies link ALS to Military Service**

Symptoms of ALS

- Fatigue
- Respiratory concerns
- Muscle weakness, stiffness, atrophy
- Muscle spasms
- Poor fine-motor coordination
- Swallowing difficulties, chewing fatigue
- Pseudobulbar Palsy
- Tongue weakness
- Weight loss
- Speaking difficulties
- Change in voice quality
- Sialorrhea (drooling)
- Mobility difficulties
- Constipation
- Depression

What does ALS look like?



What Causes ALS?

Advances in ALS research have refined our understanding of the genetics and biology of the disease.

Although we still do not know the cause of ALS, a number of diverse lines of investigation are taking place with ALS research.

- Speculation about the causes of ALS has prompted consideration that ALS may not have a unitary cause; it may represent an end-state reached through more than one pathway. If this is correct, ALS treatment may require a multimodal strategy.

ALS Diagnosis

Process of Elimination Diagnosis...

Routine tests for an ALS diagnosis establishing a diagnosis of ALS.

- EMG, an electromyogram, to study the body's nerves.
- NCV (nerve conduction velocity) which times electrical impulses travelling a length of nerve.
- A muscle biopsy determines the health of muscle tissue.

Other tests that a neurologist may use include:

- X-ray, (MRI, CAT, SPECT, or PET) for pressures on the spinal cord by tumors, cervical spine conditions, etc.
- Blood tests
- Urine tests to check for any metals in the system
- Spinal taps
- Pulmonary-function tests for breathing capacity

Psychosocial Impact



Fatal illness, 2-5 year life expectancy

Quality of life

- Needs assistance with daily living skills/personal care
- Ability to continue with employment or responsibilities
- Remaining physically and emotionally independent

Physical and emotional losses

- *“I have to let go of who I am and who I will become.”*
- Such as mobility, communication, and control
- Role in family, spousal relationship

Grieving for/by the patient and for/by family members

Decisions

- Healthcare
- End-of-life (respirators, feeding tubes)
- Estate planning, providing for family

Financial impact

- Average cost to an ALS patient is **\$200,000/year**, including cost of medicine, 24-hour care, equipment and special devices, lost wages, etc.

Treatment

Rilutek

- Currently the only FDA approved drug to slow progression of the disease.
- Can extend life expectancy for three or more months.
- Average cost is \$1,600 a month.

Symptom Management

- Providing management of the patient's symptoms rather than curing the disease.
- Quality of life.

SERVICES AND PROGRAMS

What does the St. Louis Regional Chapter actually do to help those with ALS:

The chapter offers a Continuum of Care for ALS Patients which includes: 18 in home programs free of charge – some of those are:

- **Case management Services – a full time Patient Services Coordinator assigned to each family.**
- **Information and Resource Referrals - with ALS knowledgeable specific Medical and Community Professionals and disease education**
- **Supportive Services – counseling, specialized equipment to maximize independence, and assistive technology in home consultations and nutritional supplement,**
- **Caregiver Assistance – respite, mentor programs, bereavement support and grief counseling**
- **Community Partnerships: massage therapy, ALS specific hospice programs, ALSA Center of Excellence at St. Louis University Hospital Multi-disciplinary Clinic and new Clinic at St. Francis Hospital in Cape Girardeau, MO.**

Service Overview

CONTINUUM OF CARE FOR ALS PATIENTS

HOPE

Case Management
Care Connection Network Coordination
Share our Strength Support Network
Volunteer In-Home Patient Assistance
Local and Global Research Support
Care Giver Recognition
Public Policy at Local, State And Federal Levels

EDUCATION

Education Institute for Health Professionals
Community Outreach Presentations
ALS Activity Book for Kids
Loss & Grief Manual for Families
VA Tips Manual for Veterans with ALS
Assistive Technology Options Manual
ALSource Online Medical Newsletter
Family Resource Manual

COMMUNITY PARTNERSHIPS

Gold Star Certified Network of Service Providers
Collaboration with Massage Therapy Schools
Community Service Opportunities for Schools and Groups
Augmentative Communication Assessments with Colleges
Alliance with Department of Veterans Affairs
Nightingale Program-In Home Modification Assessment Planning

PATIENT AND FAMILY PROGRAMS

*Serving Eastern Missouri
Central & Southern Illinois
since 1984*

*All services are free of charge
to patients & families*

HELP

Home Visits
Community Referral Network
In Home Medical Respite Care
Home Accessibility Modification Grants
Nutritional Supplement Support
Clinic Transportation Assistance
Durable Medical Equipment Loan Closet
Assistive Technology Loan Closet
Speech Generating Device Loan Closet
Computer Access Support
PT,OT, and Speech Therapy
ALS Specific Medication Support
Counseling for Patients and Caregivers
Counseling for Children
Blue Tooth Technology Grants

HEALTH

ALS Center of Excellence
St. Louis University Health Sciences
Center in St. Louis, Missouri

ALS Recognized Treatment Center
St. Francis Medical Center in
Cape Girardeau, Missouri



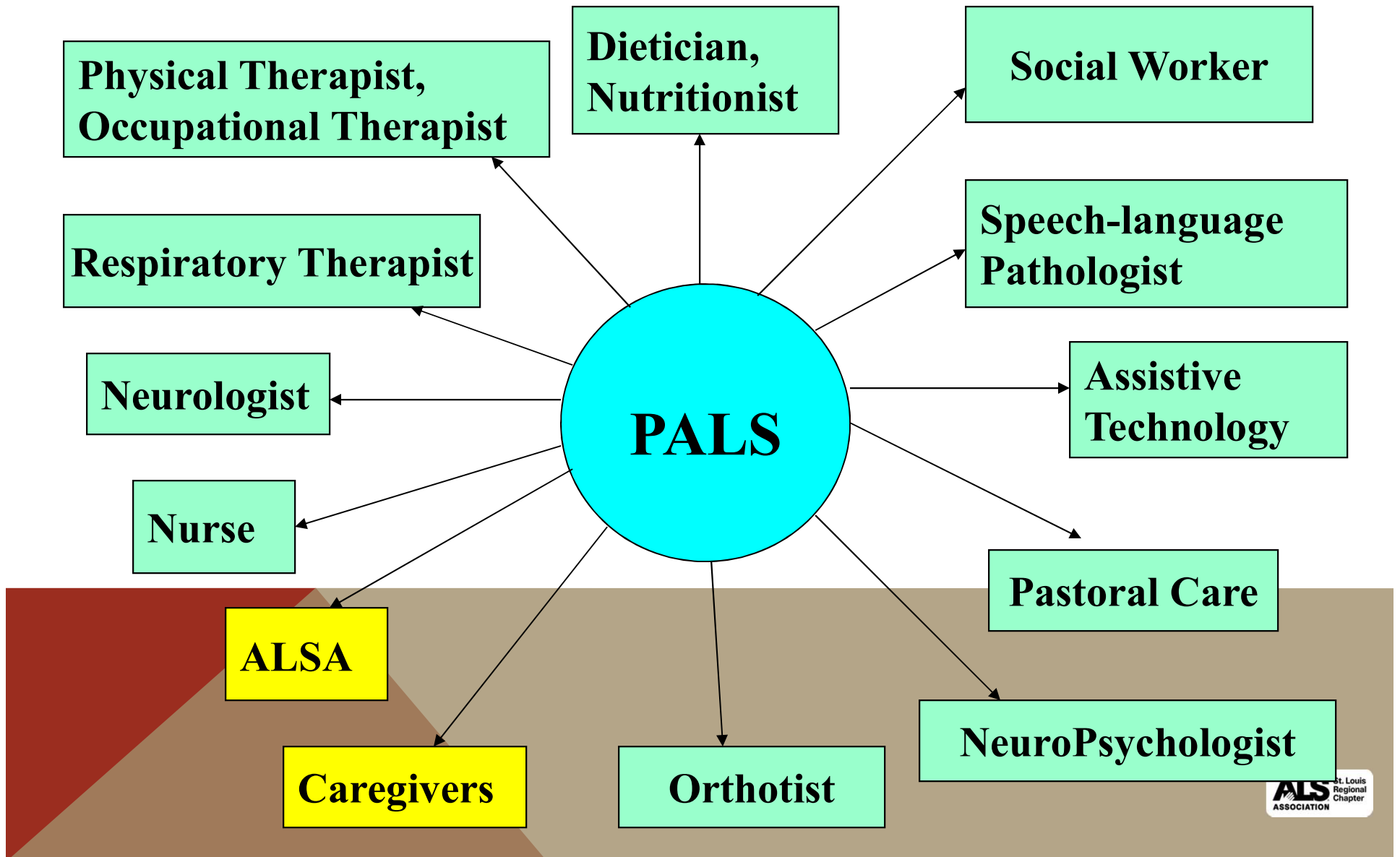
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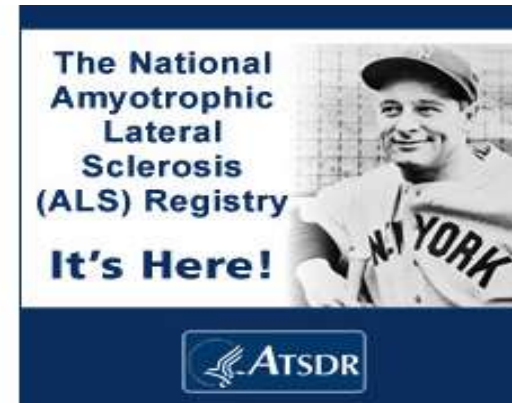
ALS Certified Centers of Excellence

- **St. Louis University ALSA Certified Center**
- **St. Francis Medical Center**
- **Adding 2 VA Clinics**
- **MDA Neuromuscular Clinics - not ALS specific**
- **Clinic approach extends a person's life by 12 month.**

Health Management Team



Furthering our Understanding



In 2010, the CDC established a national ALS patient registry to identify ALS cases in the US and collect information urgently needed for ALS research.

www.cdc.gov/als

Taking the Next Step

- **Become a Corporate Partner**
- **Volunteer**
- **Walk to Defeat ALS**



- **Be Aware**
- **Be Knowledgeable**
- **Be Patient**
- **Be Creative**

It's Not Just Lou's Disease

