

Welcome to the “ALS Starter Kit” Webinar

*Important things to know when new to the
ALS community*

Presented by:

- **Peggy Allred, Physical Therapy Clinical Specialist**
- **Rebecca Axline, Clinical Social Worker**

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Access code: 660 748 171



Peggy Allred & Rebecca Axline



Webinar co-hosts Rebecca & Peggy.

Peggy Allred, PT, DPT, is a physical therapy clinical specialist and genetics program coordinator at the Washington University School of Medicine in St. Louis.

Rebecca Axline, LCSW, is a clinical social worker with Methodist Hospital's Neurological Institute in Houston.

Outline

- Sharing the News
- ALS Team Members & their Roles
- Patient-Centered Care
- Continuum of Care
- Empowerment
- Planning Ahead

Sharing the News

- Many say that receiving a diagnosis of ALS is overwhelming
- No right or wrong method for telling others
- How much you tell others is your choice
- It's important to begin to form your "Care Team" or "Care Network"
- myMuscleTeam® www.mda.org/myMuscleTeam

The Next Step

- Find an MDA/ALS Clinic - www.als-mda.org/locate.html
- Understand that MDA/ALS diagnostic teams can differ depending on your location
- Explore resources for valid, current information and research trials
- Continue educating yourself and seeking information

Clinic Team Members & Roles

- Each MDA/ALS clinic is unique
- Team members may have multiple roles
- Use your team as a resource
- Utilize MDA resources to find health care providers familiar with ALS
- Use MDA internet resources for current, valid information

Team Members

- Neurologist
- Pulmonologist
- Nurse
- Physical Therapist
- Occupational Therapist
- Speech Pathologist
- Respiratory Therapist
- Dietitian/Nutritionist
- Social Worker
- Neuropsychologist
- Research Coordinator
- Chaplain/Rabbi
- Financial Planner/Attorney
- Equipment Specialist

Team Members cont.

■ Neurologist

- Performs neurological & diagnostic exams
- Assess disease progression; makes recommendations for care
- Manages medications



■ Pulmonologist

- Manages & interprets pulmonary function aspect of ALS
- Makes recommendations

■ Nurse

- May serve as Clinic Coordinator
- Triage patient care issues
- May assist with medication management and refills



Team Members cont.

■ Physical Therapist

- Assesses gross motor function such as walking & transfers
- Will advise on exercise & equipment needs



■ Occupational Therapist

- Assesses fine motor function such as dressing, feeding & person hygiene
- Assesses home safety issues

■ Respiratory Therapist

- Performs pulmonary function to assess breathing status



Team Members cont.



■ Speech Pathologist

- Assesses issues with speech & communication
- Assesses swallowing function
- Will advise on Augmentative communication devices

■ Dietitian/Nutritionist

- Assesses nutritional status
- Will monitor weight & make dietary recommendations

Team Members cont.

■ Social Worker

- Provides information about resources & assists in understanding eligibility status
- Advocates for obtaining necessary resources
- Emotional counseling

■ Neuropsychologist

- Baseline evaluation of cognitive function
- Follow-up testing if necessary or if concerns are expressed



Team Members cont.

- Research Coordinator
 - Assesses eligibility for Clinical Research opportunities
 - Primarily responsible for the day-to-day activities of clinical trials
- Chaplain/Rabbi
 - Spiritual support & clarification
- Financial Planner/Attorney
 - Consults to assist in making effective choices & understanding financial resources
 - Consults regarding legal matters

Team Members cont.

- Equipment Specialists

- Wheelchairs

- Respiratory Equipment

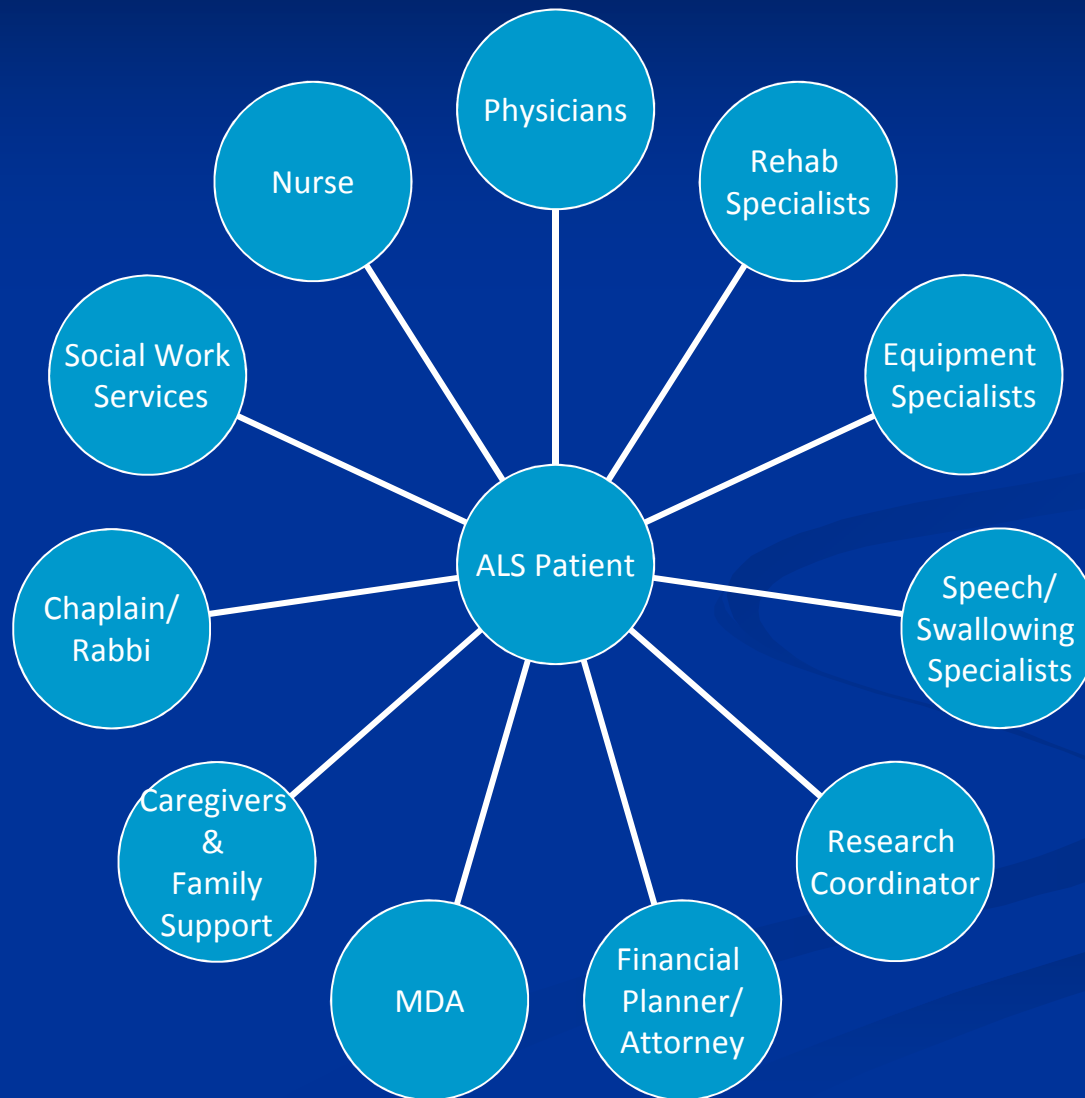
- Bipap
 - Suction machines
 - Ventilators

- Orthotics

- Augmentative Communication Devices



Patient Centered Care



Continuum of Care

- Early intervention is strongly encouraged
- Proactive management of symptoms can ease the disease burden
- Weigh pros and cons of care decisions
- Include your Care Network in the discussion
- Decisions about care are personal and individual – have difficult conversations when necessary

Empowerment for Care Decisions

- Keep a notebook
- Ask questions
- Seek information
- Be aware of your options
- Utilize your supportive community
- Don't save all questions for clinic – contact when you need answers



Empowerment

■ Advocacy Networks

- CDC registry www.cdc.gov/als
- Governmental issues
- Local access issues
- Online networks
- Become an advocate
 - MDA Advocacy www.mda.org/advocacy



■ Give back to your community

- Fundraisers
- Places of worship

Planning Ahead

- Choosing options and checking eligibility
 - Short/long-term disability
 - Social Security Disability
 - Medicare or private insurance
 - Veterans benefits
 - Other state or community programs
 - Private foundations or funds

Planning Ahead

- Equipment
 - Early intervention
 - Safety
 - Eligibility
 - Funding
- MDA Loan Program



Planning Ahead

- Discuss interventions with your physician and team
- Explore options for help at home
- Discuss your wishes for Advance Directives
- Having difficult conversations with family and your team



Putting your Resources to Work for You

- Knowledge is Power
 - Practice Parameters
 - MDA Publications
 - Clinic Visits
 - Support Groups
- Managing Care Decisions
 - Utilize your Care Network's knowledge
 - Advance Directives
 - Five Wishes Document



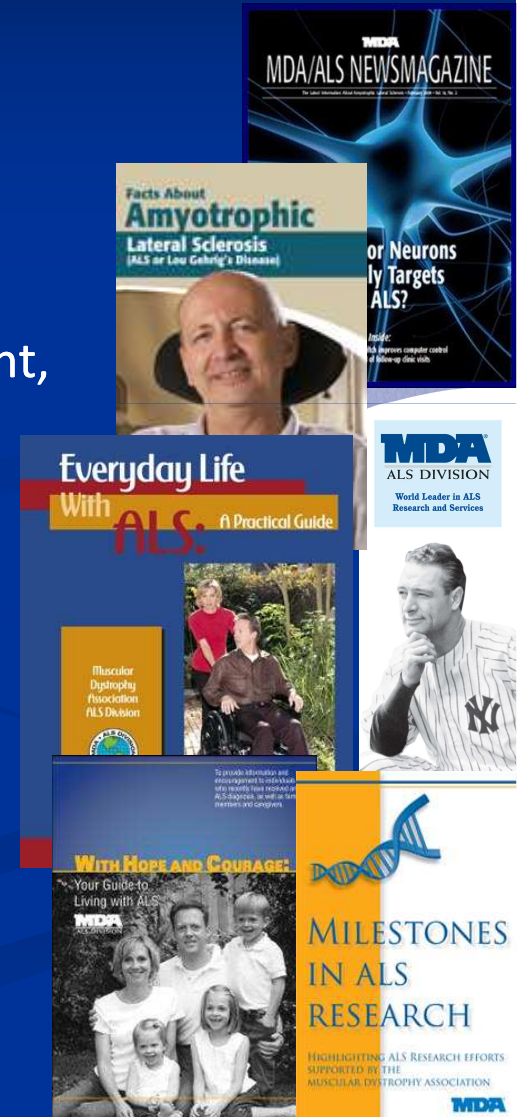
Important Resources

■ ALS Practice Parameters

- Original document published in 1999; updated in 2009. Published in Neurology, October 2009.
- Review of Evidence in the Management of ALS
- Covers Multidisciplinary Care, Symptom Management, Cognitive/Behavioral Impairment, and Drug,
- Nutritional and Respiration Care Therapies

■ MDA Publications & Videos

- *Everyday Life with ALS: A Practical Guide*
- *MDA ALS Caregivers Guide*
- “With Hope & Courage” DVD



General Principles

- Visit your neurologist/clinic team regularly
- Maintain your weight
- Moderate activity levels are beneficial
- Safety First
- Monitor your insurance/funding situation
- Stay engaged and involved

Questions?

MDA[®] Muscular
Dystrophy
Association
ALS DIVISION

Thank You!

Today's webinar will be archived and available for viewing on MDA's website at www.mda.org/services/webinar.html.

For additional questions, please contact the MDA Health Care Services Department at healthcareservices@mdausa.org.

For more information, please visit www.als.mda.org.

