Building Your ALS Team from the Ground Up

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St. Louis VA Medical Center, St. Louis, Missouri
PVA Summit 2018
Disclosures

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Learning Outcomes

At the conclusion of this activity, the participant will be able to:

1. Identify five key disciplines involved in VA ALS Clinics.
2. Identify two challenges in providing multidisciplinary care to veterans with ALS.
3. Describe a typical patient experience in an ALS Multidisciplinary Clinic.
Background

John Cochran VA Medical Center
Grand Blvd.

Jefferson Barracks
South St. Louis County along the Mississippi River
Must Dos in St. Louis

- Ted Drewes’ Frozen Custard
- Gateway National Expansion Monument (The Arch)
- Gus’ Pretzels
- Anheuser-Busch Tour
- St. Louis Zoo

- The Magic House
- Busch Stadium and Ballpark Village
- Crown Candy Company
- Forrest Park (Muny, Zoo, Art Museum, and Science Museum)
- Trivia Nights
- Food Trucks
Multidisciplinary care for ALS has been shown to increase life expectancy and quality of life.
Background of Clinic

Organizing meetings were held in early 2016

- Disciplines Involved:
  - Neurology Clinic
  - Spinal Cord Injury
  - Associate Chief, SCI/D
  - Occupational Therapist
  - Physical Therapist
  - Psychologist
  - Social Worker
  - Palliative Care
  - Speech & Language Pathology
  - Registered Dietitian
  - Physical Medicine & Rehab
Who Else Should Have Been Invited

Invited:
- Primary Care
- Respiratory Therapist
- Prosthetics
- Home Based Primary Care (HBPC)
- Pulmonology
- Paralyzed Veterans of America
Someone to Coordinate is Essential

- Neurology NP hired in Summer 2016; started role in December 2016
- Coordinated meetings
- Included ALS Association
The STL VAMC ALS Team

- Nurse Practitioner/ALS Coordinator
- Neurologist
- ALS Association Representative
- PVA National Service Officer
- Social Worker/Case Manager
- Dietitian
- Occupational Therapist
- Physical Therapist
- Psychologist
- Speech Language Pathologist
Coordinator’s Role

- Nurse Practitioner
- 51% Clinical for ALS, generalized neurology, and MS
- 49% Administrative for general neurology
- Point person between visits
- Identify potential patients/scheduling
Neurologist/ Neuromuscular Specialist

- Recruited part-time from Washington University in St. Louis
- Started in May 2017
- Has an additional clinical day for diagnosing ALS and treating other motor neuron diseases
- Ability to perform EMG onsite
- Unofficial duty: Recruits veteran patients
ALS Association Representative

Tara Klucker...
• Advocates for Veterans with ALS (VALS)
• Identifies needs that ALS Association can provide.
• Maintains database registration.
• Provides home visits for emotional support.
• Oversees patient satisfaction surveys.
PVA National Service Officer

- Connect veterans with VA benefits
- Advocate for veterans
- Identify when veteran qualifies for increase in level of support/Aid & Attendance
Social Work

- Provide resources to achieve highest level of functioning at home
- Caregiver support
- Work with other team members to maximize benefit use
- Assist with issues of adjustment for both veteran and caregivers
- Provide support along continuum of care to increase services as needed, find placement if veteran’s needs cannot be managed at home, develop plan for respite
- Assist with completion of Advanced Directives
Dietitian

- Assess current nutrition status
- Order appropriate nutritional supplements
- Assist veterans and family to transition to tube feedings
- Assess and assist with any special dietary practices/cultural needs
Occupational Therapist

- Complete initial and regular, ongoing evaluation to determine status of upper extremities, functional status, home access, vehicle access, education and training needs.

- Overall goal of OT being that a person with ALS continues to find as much Quality of Life as possible throughout the disease progression.
Occupational Therapy Continued

- Home evaluation to determine access and equipment needs
- Ensure appropriate Durable Medical Equipment is in place in the home
- Provide training and adaptive equipment to prolong ability for self-care as long as possible
- Evaluate for and provide appropriate upper extremity orthotics
- Educate and provide assistive technology
- Educate in energy conservation principles and guide veteran with ALS to make best choices regarding which tasks to pursue in a given day
- Educate in vehicle modifications
- Encourage and enable community access
Physical Therapist

- Assess for any mobility equipment
- Arrange for appropriate seating and fitting of mobility equipment
- Help clients maximize and maintain mobility
- Order any appropriate DME and lower extremity orthoses
Psychologist

- Assess for any adjustment issues and provide appropriate counseling/therapy
- Family and caregiver support
Psychology Resident

- Conduct neuropsychological screening to assess cognitive and behavioral functioning
- Provide psychoeducation on compensatory strategies to assist with cognitive weaknesses
- Provide a Cognitive Rehabilitation Group as a resource to Veterans
Speech Language Pathologist

- Evaluate, provide intervention, and monitor the mechanisms and functions of
  - Cognition
  - Language
  - Speech
  - Swallowing
  - Voice
Connect with an Established Clinic

- Find an ALS Recognized Treatment Center in your area and ask to shadow.
- Look at list of Recognized Treatment Centers and reach out for help.
First ALS Clinic

May 5, 2017➔ Radicava gets FDA approval

May 19, 2017➔ First St. Louis ALS Clinic day

September 26, 2017➔ First Radicava dose administered at St. Louis VA
Challenges

Clinic Space
Patient Rotates vs. Professionals Rotate
2 floors of Medical Center
• Neurology Clinic 1st Floor; across from main elevator
• 7th Floor Inpatient/Acute Spinal Cord Injury Unit utilize PT/OT gym and conference room
• Conference room for “Huddle”
Challenges

• Lack of available computers/laptops for documentation
• Use of clinical space for other concurrent clinics
• Scheduling follow-up appointments
• Obtaining accurate weights on clinic scales
• Respite care and long term care for veterans who are ventilator dependent
• Some veterans only come for ALS Team Care and then request ALS Team to perform Primary Care Functions
Challenges

With multiple services involved: Home Based Primary Care, Palliative Care, ALS team, who is driving the bus when there are three social workers, three therapists, etc.
Advantages

• Related disciplines perform related assessments together ie: OT and PT, speech and dietitian
• Gym available to demonstrate equipment
• PT can perform onsite wheelchair assessments
• PT/OT shared with Spinal Cord Injury- increased knowledge of high tech equipment
• Availability of SCI Conference Room for IDT meetings
Successes

- 30 individual veterans served
- PT/OT/SW home visits
- Feeding tube repositioned by Interventional Radiology during clinic appointment
- Palliative Care readily available
- Battlefield Acupuncture performed
- 14 veterans have received Radicava
Supports from Other Disciplines

- Ambulatory Evaluation and Treatment Center (AETC)
- Community Health
- Clinical Pharmacist
- Veteran Video Connect
- Transportation
- Home Health Aide Program/Veteran Directed Care
Supports from Other Disciplines

- Prosthetics
- Oxygen/Ventilator Provider
- Home Based Primary Care
- Interventional Radiology
- IV Therapy Services
Typical Patient Experience

- Arrive at 8:30, 9:30, 10:30 or 11:30; staggered times; new patients no later than 9:30
- Check-in at Neurology Kiosk, Vital Signs
- Either stay in Neurology or go up to SCI (7th floor)
- 7th Floor: PT, OT, SLP, RD
- Neurology: MD/NP, SW, psychologist, PVA representative, ALS Association representative
- Veteran rotates to disciplines (sees all in SCI are or all in Neurology)
- Escorted by staff member
- Make any specialty appointment stops (PFTs, Palliative Care, Pulmonology)
- Schedule follow-up appointments, home visits, Radicava infusions
- About 3 hour total appointment times
Augmentative and Alternative Communication

• SAAC group meets on the 2nd and 4th Friday of each month for two hours in the afternoon.
• Group consist of the Veteran, spouse/caregiver, speech language pathologist, and speech generating device representative.
• GOAL OF CLASS: Provide Augmentative & Alternative Communication (AAC) education to Veteran's diagnosed with ALS - Using some other way to communicate in support of, or as an alternative to speech.
Advantages For The SLP When Conducting An AAC Group

- Allows the clinician to monitor and conduct future planning for AAC treatment with ALS which involves determining how the device can be modified and/or adapted to meet the Veteran’s communication needs as the disease progresses and the physical needs change.
Advantages For The Veteran When Participating An AAC Group

- Veteran’s provided with the opportunity to learn and teach one another with using their devices.
- Built-in Veterans with ALS (VALS) Support Group
Beyond The AAC Group

- Spending time with the caregivers within the class setting revealed intellectual and emotional challenges that the caregivers were enduring.
- Coordination with VA Caregiver Support resulted in the opportunity for caregivers to meet with a provider during the time of the class meeting to address/discuss the responsibility of caring for someone else, caring for themselves, and their overall needs/concerns/questions.
- VA Caregiver Support provider is now assisting with gathering the needs of these caregivers to develop an ALS caregiver support group.
Numerous teams participated in the annual St. Louis Walk to Defeat ALS® 5k Walk event on 6/23 in the Forest Park Upper Muny Parking Lot. In addition to the walk, there was a lot of free food, giveaways, and information booths on site. Pictured (from left): Tara Klucker, Director of Programs and Evaluation/ALS Association, Jeremy Lile, National Service Officer/Paralyzed Veterans of America, and Anndee Glick, Nurse Practitioner/Neurology Department/John Cochran VAMC.
Over the past 11 months, ALS robbed Dick of the ability to speak, swallow, walk, and eventually to breathe. Despite those challenges, he never lost his sense of humor and inspired so many people by dealing courageously with this cruel disease through his strong faith. He and his family also were grateful for the outstanding medical care from the ALS team at the VA Medical Center John Cochran Division in St. Louis. . .
QUESTIONS?????

"I might have been given a bad break, but I've got an awful lot to live for."

Lou Gehrig

July 4, 1939
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