ALS Multidiscipline Care
The Minneapolis VA Experience

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Learning Objectives

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

• 1. Recognize and value the duty to serve Veterans who have ALS.
• 2. List at least three benefits of multidiscipline ALS care.
• 3. Be prepared to help the ALS patient to avoid or mitigate crises.
Amyotrophic Lateral Sclerosis

- **September 2008**: Congress and the Department of Veteran Affairs established presumptive Service Connection for ALS

- Veterans with ALS and their survivors became eligible for full healthcare and disability benefits.
Our Duty to Veterans

• "The willingness with which our young people are likely to serve in any war, no matter how justified, shall be directly proportional to how they perceive the Veterans of earlier wars were treated and appreciated by their nation."

• President George Washington
Our Responsibility to Veterans Who have ALS

• As result of Service Connection for ALS, the VA is charged with the **responsibility** to:

  • Provide support and treatment to maximize quality of life, manage symptoms, lessen emotional and physical suffering.
ALS Life Expectancy

- Median survival: 3 years
- Long term invasive ventilation: 15 years or longer

- From diagnosis to death, the needs are many.

- ALS affects all aspects of life, therefore, all aspects warrant attention.
Minneapolis SCI/D Experience

- **SCI/D** traditionally provides rehabilitation and sustaining care to Veterans with spinal cord injury/disorders.

- **Traditional Rehab focus**: maximize function and independence, prevent secondary problems while anticipating a close to normal life span.

- **ALS patients are appropriate and a good fit for SCI/D System of Care** because of the multidiscipline focus, expertise for functional loss, and caregiver issues, however, may not be experienced with rapid progression of disease, death and dying.
Minneapolis SCI/D Experience

• Minneapolis SCI/D serves VISN 23 which includes all of Minnesota, the Dakotas, part of Nebraska, part of Iowa and western Wisconsin.

• Our ALS clinic has served patients from Minnesota and Western Wisconsin thus far.

• It is preferred that patients receive care close to home if possible to reduce the burden of travel.
Minneapolis SCI/D Experience

- **Data 2010-Present:**
  - 119 Veterans with ALS served
  - 38 deceased
  - 81 patients alive
  - 1-3 new ALS patients/month
  - 5 patients have elected invasive ventilation –about 6%
  - ALS represents about 10% of our population served
  - Four clinic days/week for ALS
  - 30 bed **inpatient unit**, 4 that are **ventilator** ready.

**Competition for clinic time**, hospital beds, in particular, ventilator-ready hospital rooms.
Minneapolis SCI/D Experience

- Patients are seen every 3 months by the ALS Team
- A full day of appointments.
- Downside: fatigue, information over-saturation
- Downside: schedule is rigid.
- Upside: One Stop Shop
- Some opt to divide into two days
- PRN and a la carte options
Minneapolis SCI/D Experience

- **Support and Networking**
  - Patient and Caregiver Support Group
  - Monthly ALS Team meetings for staff
  - Quarterly ALS Community Network meetings sponsored by the ALS Association:
    - VA
    - University of Minnesota ALS Clinic
    - Hennepin County Medical Center ALS Clinic
    - Mayo Clinic, Rochester ALS Center
Minneapolis SCI/D
Invasive Ventilation

• National data: 5-10% persons with ALS elect to have invasive ventilation.
• St. Cloud CLC, 10 ventilator beds
• Limited community long term vent beds.

• Minneapolis VA thus far: 5 persons, about 6%

• Four living at home, none in community long term care facility, one at St. Cloud VA CLC

• One awaiting placement, complicated due to TPN.
Multidiscipline Care

• A Centrally Managed Team can provide multidiscipline care in an efficient and comprehensive manner.

• The advantages of a centrally managed system of care benefits:
  • Patient
  • Caregivers
  • Professional staff who are serving the veteran
Centrally Managed Team Effect

- **Coordination** of appointments, reduced travel, efficient service
- Enhanced *communication among professionals*
- **Expertise of the whole**: greater than as individuals
- Establish protocols, research, correct deficiencies, *improve efficiency* as a team.
- Improved job satisfaction, *working as a team* rather than isolated and overwhelmed.
Who is on Your ALS Team?

- **ALS Team:**
  - Occupational Therapy
  - Physical Therapy
  - Rehab/Neuro Provider
  - Psychologist
  - Speech Therapy
  - Prosthetics
  - Assistive Technology Specialist
  - Pulmonologist
  - Respiratory Therapy
  - Dietitian
  - Wound Ostomy Nurse
  - RN Case Mgr./Coord.
  - Chaplaincy, Pastoral Care
  - Pharmacist

- Primary Care Provider: local care preferred
- Home care agency, private-hire care, family, friends
- Palliative Care/Hospice
- Telehealth, Telemedicine
A “few” of the Needs

• **Symptom management**: medications, referrals
• **Communication** devices, training
• **Feeding tubes**, nutrition education
• **Equipment**: adaptive devices, splints, wheelchairs, hospital bed, mattress, ramps, vehicle adaptation
• **OT/PT**: spasticity management, energy conservation, fall prevention, home evaluation, caregiver training.
• **Support at home**, home care, Telehealth, home respiratory equipment, respite.
• **Mental Health**: Cognitive impairment, adjustment, coping, pre-morbid MH problems.
• **Palliative Care/Hospice**: prepare for the end, live well in the meantime, advanced directive, POA.
Resources
Multidiscipline Care: Cost?

ALS cost and benefit studies in Netherlands:

- **Cost** of multidiscipline care was similar to that of general care:
  
  €1336 vs. €1271 per month.
  
  (Approx. $1,691 vs. $1,609 per month)

  However,

  **Outcomes differed:** those receiving multidiscipline care reported better quality of life.

- Van den Berg, 2005
- Van der Steen, 2009
What is VERA?

- **VERA**: Veterans Equitable Resource Allocation
- Encounter forms track diagnoses and cost.
- Some diagnoses represent greater reimbursement.
- For example,
  - “Amyotrophic Lateral Sclerosis” $------
  - “Paraplegia” $
  - “Quadriplegia” $
  - “Loss of use” one limb $
  - “Dysphagia” $
ALS Experience

• Dilemma: Great needs, high cost, no high VERA
• Strain on budgets and staff.

• HOWEVER,

• We must not lose site of our mission to provide excellent care to these deserving Veterans.
Prepare, Prepare, Prepare

• Not “if”, but “when” A realistic understanding of the disease process and what that will mean.

• The “cliff effect”, thresholds when systems break down suddenly.

• This is critical patient/caregiver education.

• Look back to see what may lie ahead.
A Moving Target

- **Constant re-evaluation** required in all spheres.
- Look at the patient comprehensibly at **each** visit.
- What worked last month, is no longer effective, or a new problem has emerged.
- **Ripple effect** of new or worsening problems
- **Accommodations** such as power wheelchairs, training for communication devices, **take time**.
- **Need for vigilance**: watch for approaching icebergs!
Plan Ahead

- Power wheelchair?
- Housing Adaptations?
  - Accessible van?
- Electronic Communication Equipment

- VA “Clinical Practice Recommendations for Motorized Wheeled Mobility Devices”

- Section IV. Indications/Contraindications:
  “The patient has progressive disease that is likely to cause limitation such as (upper and lower limb function), within a year.”
CRISIS

• A medical, social, or emotional crisis creates:
  • Spike in stress and anxiety for all involved
  • Almost always emotionally charged
  • Contributes to a reduced ability to problem solve
  • Options are limited
  • Important decisions under duress
  • Pressure of time, intervention was needed yesterday or last month.
  • Crisis is unplanned for, patients do not have a scheduled appointment to have a crisis!
AVOID CRISIS!!

Patterns to watch for:

• **Respiratory decline**, falling pulmonary function, increased work of breathing

• **Falls**, increased fatigue

• **Need for food texture change**, aspiration, choking, weight loss, dehydration, inability to take pills.

• **Caregiver burnout**: increased demand, physical fatigue, anger, emotional fatigue, injuries, other family and work responsibilities.

• **Dysarthria**: breakdown in communication, frustrations, only one person who can interpret.

• Patients and families as well as the ALS Team should be made aware of these patterns so they can **avoid crisis**
We have Crisis

• The ALS Team is stretched, providing for a multitude of ever changing needs for complex patients.

• A patient crisis often translates into a Team crisis.

• Avoiding crisis is obviously good for the patient and family; it is also good for the ALS Multidiscipline Team.
Avoiding Staff Crisis

- **An ALS Team Support group**: share information, problem solving, also a format for emotional support to fellow professionals experiencing emotional fatigue caring for the suffering.

- **Favor regular meetings** with an agenda, record minutes, keep track of projects.

- **Discuss** systems issues, program development
ALS: The Uninvited Guest

• ALS is a devastating disease to experience and to observe.

• It is our charge to do what we can to ease the burden of this disease for the patient and his/her loved ones.

• The ALS Team comes along side the patient, to help, to encourage, and to draft the wind for him/her as they run this race and help provide comfort as they reach the end.
The Future of VA ALS Care

• Allocation of high VERA Dollars?

• **Opportunities** for research, development of local, national database

• Create **local networks** with non-VA ALS Clinics.

• Establish a **Special Interest Group** for ALS through the PVA Summit

• Work with **ALS Association** to become Certified Centers

• **VA Handbook for Care.**
Veterans

• "The willingness with which our young people are likely to serve in any war, no matter how justified, shall be directly proportional to how they perceive the Veterans of earlier wars were treated and appreciated by their nation."

• *President George Washington*
• Thank you for your attention today and

• Thank you for your dedication to provide excellent care to Veterans with ALS.
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