Outpatient Care Management of Veterans with ALS

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Brigitte Lee, MSW, LCSW has no financial interest to disclose.

Patricia Beat Reisinger, MS, CCRN, FNP, GNP has no financial interest to disclose.
Learning Objectives

The learner will:

* Describe the current state of ALS care in the VA Health Care System.
* Discuss VHA Handbook draft 1101.07 directives and how to meet the charge prescribed in *Amyotrophic Lateral Sclerosis (ALS) System of Care Procedures*
* Describe how the Eastern Colorado Health Care System’s outpatient SCI clinic located at the Denver VA Medical Center provides services to Veterans with ALS.
Learning Objectives Continued:

* Illustrate the role of the nurse practitioner in coordinating medical symptom relief and medical case management to Veterans with ALS by integrating palliative care.
* Examine the role of the Licensed Clinical Social Worker in providing psychosocial case management to Veterans with ALS and support their family and caregivers.
* Evaluate the case study presentation on the strengths and limitations of care to Veterans with ALS.
INTRODUCTIONS
Brigitte Lee, MSW, LCSW

- Obtained Masters Degree in Social Work from the University of Denver School of Social Work in 1999.
- Licensed Clinical Social Work in Colorado since 2001
- Medical Social Worker for 18 years
- Denver VA Medical Center for 12 years
- SCI/D program coordinator for 2.5 years
Patricia Beat Reisinger, MS, CCRN, FNP, GNP

- Masters of Nursing University of Colorado 1986, Post-Masters, FNP University of Wyoming 2000
- University of Colorado Palliative Care Certificate 2012.
- SCI-Nurse CareCure.org Forum, WM Keck Center for Collaborative Neuroscience-The SCI Project, Rutgers
- Rocky Mountain Chapter ALS Association Board Member since 2010, Patient Services Committee Chairperson.
AMYOTROPHIC LATERAL SCLEROSIS (ALS) SYSTEM OF CARE PROCEDURES
VHA HANDBOOK 1101.7
*DRAFT*
August 2012 the ECHCS SCI/D team got its first glance at the Amyotrophic Lateral Sclerosis (ALS) System of Care Procedures Handbook 1101.7.

Second draft received on August 13, 2013 and comments were submitted August 22, 2013.
Excerpt

Purpose:

The Veterans Health Administration (VHA) Handbook establishes procedures for health care and services to Veterans with Amyotrophic Lateral Sclerosis (ALS). It describes the essential components and procedures of the ALS Program that are to be implemented nationally to ensure that all enrolled Veterans, wherever they live, have access to ALS care. Necessary structural, procedural and educational components for consistent ALS services are described....
Excerpt
Background:

A study released by the Institute of Medicine on November 10, 2006, *ALS in Veterans: Review of the Scientific Literature*, concluded that “there is limited and suggestive evidence of an association between military service and later development of ALS”.

This finding prompted the Secretary of Veterans Affairs, James R. Nicholson to make the decision that ALS will be a compensable illness for all Veterans with 90 days of continuously active service in the military.
Background cont...

- Approximately 3,600 Veterans with ALS received care from VHA between FY 2005 and 2009 with 1,400 dying by the end of this period.
- On average, 1,520 Veterans with ALS are seen in VHA in any fiscal year.
- The IOM study noted a 1.5 fold increased ALS incidences in Veterans suggesting an annual incidence rate of 4.5 per 100,000 Veterans, yielding an estimated annual incidence of 1,055 Veterans with new onset ALS and a possible Veteran prevalence of 4,220 given current life expectancy exceeding 3 years.
Scope

Interdisciplinary ALS care has been shown through research to improve patient outcomes, including life expectancy and quality of life.

Eastern Colorado Health Care System is designated as VISN 19 point of care for Veterans with diagnosis of ALS
VHA Handbook Draft 1101.07 directs that the ALS interdisciplinary team “needs” to include

- ALS Physician and Primary Care Provider
- APRN or CNRN that
  - Has competencies documented and protocols in place to support the Veteran and Caregivers.
  - Provides support to the Veteran and Veteran’s family using face to face meetings, televideo conferencing, telephone, or secured messaging.
  - Serves as case manager, coordinating PACT care and non-VA care into the Veteran’s health care plan.
  - Identifies, addresses and engages the team in the management of care issues.
ALS TEAM CARE cont....

- Palliative Care or Hospice Care Team Staff member
- HBPC Team staff member
- Speech-Language Pathologist
- Physical Therapist
- Occupational Therapist
ALS TEAM CARE cont...

* Pharmacist
* Psychologist (Clinical Health Psychologist, Rehabilitation Psychologist)
* Dietician
* Pulmonologist
* Respiratory therapist
ALS TEAM CARE cont....

- Social Worker
- Therapeutic Recreation Specialist
- Assistive Technology Specialist
- ALS Association representative (with the patient’s consent)
- Chaplain from the patient’s preferred faith or religion
ALS TEAM CARE cont....

* Gastroenterologist (as consultant)
* Veteran benefits liaison (as consultant at the Veteran’s request)
  * Veterans Service Organizations
    * PVA
    * DAV
    * State Veterans Service Officers
100% Service Connection

* Federal Register September 23, 2008 73 FR 54691 A final rulemaking establishing a presumption of service connection of ALS for any veteran who develops the disease at any time after separation from service.
ALS Consults 2001-2013
Veterans with ALS: Encounter Data

<table>
<thead>
<tr>
<th>YEAR</th>
<th>Encounters</th>
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<tbody>
<tr>
<td>2005</td>
<td>256</td>
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<tr>
<td>2006</td>
<td>146</td>
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<tr>
<td>2007</td>
<td>243</td>
</tr>
<tr>
<td>2008*</td>
<td>122</td>
</tr>
<tr>
<td>2009</td>
<td>433</td>
</tr>
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</table>

*Year of 100% service connection
2010-2013 Veterans Age at ALS Diagnosis

- 81+
- 71-80
- 61-70
- 51-60
- 41-50
- 31-40
- Under 30

The chart shows the age distribution of veterans diagnosed with ALS between 2010 and 2013.
2010-2013
Time from diagnosis to death

- 5 yr +
- 4 yr
- 3 yr
- 2 yr
- 1 yr
- 9 mos
- 6 mos
- 3 mos
- 1 mos

Time from diagnosis to death
### 2010-2013 Statistics

<table>
<thead>
<tr>
<th>Category</th>
<th>Count</th>
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<tbody>
<tr>
<td>Current Veterans</td>
<td>33</td>
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<tr>
<td>Deceased</td>
<td>26</td>
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<tr>
<td>Not served</td>
<td>3*</td>
</tr>
<tr>
<td>Married</td>
<td>55</td>
</tr>
<tr>
<td>Not Married</td>
<td>8</td>
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<tr>
<td>Male</td>
<td>56</td>
</tr>
<tr>
<td>Female</td>
<td>2</td>
</tr>
<tr>
<td>Moved to CO</td>
<td>4</td>
</tr>
<tr>
<td>Moved from CO</td>
<td>2</td>
</tr>
</tbody>
</table>

*out of area/state
### 2010-2013 Services and Location provided at death

<table>
<thead>
<tr>
<th>Location</th>
<th>Count</th>
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<tbody>
<tr>
<td>VA HBPC</td>
<td>13</td>
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<tr>
<td>Hospice</td>
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<tr>
<td>Home care only</td>
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<tr>
<td>Unknown</td>
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<tr>
<td>Community NH</td>
<td>9</td>
</tr>
<tr>
<td>VA CLC</td>
<td>3</td>
</tr>
<tr>
<td>Hospital</td>
<td>2</td>
</tr>
<tr>
<td>Home</td>
<td>11</td>
</tr>
<tr>
<td>Location</td>
<td>Count</td>
</tr>
<tr>
<td>----------------------------------------------</td>
<td>-------</td>
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<tr>
<td>Community Neurologist</td>
<td>18</td>
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<td>University Hospital Neurology*</td>
<td>13</td>
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<tr>
<td>Kaiser</td>
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<td>VA System</td>
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<td>Community Interdisciplinary ALS clinic</td>
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<tr>
<td>Second Opinions **</td>
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</tbody>
</table>

*in state and out of state University program
**more than one neurologist consultation or confirmation of diagnosis
SCI/D INTERDISCIPLINARY TEAM

- Physiatrist Attending MD
  - Rehabilitation Resident MD
- Nurse Practitioner
- Licensed Clinical Medical Social Worker
- Physical Therapist (mobility, lifts)
- Occupational Therapist (home evaluations and adaptations, bathroom equipment, driving evaluations)
- Speech Pathologist (speech and swallow evaluations)
- Palliative Care Psychologist (Palliative Care Team liaison)
SCI/D INTERDISCIPLINARY TEAM cont...

- Wheelchair clinic (customized & power mobility)
- Assistive Technology (Specialized computer and software for limited hand motion/control, eye gaze communication device/software)
- Prosthetics (HISA grants, vehicle adaptations)
- PVA Service Officer
- Recreational therapy, as needed
- Dietician, as needed, veterans with PEG
ALS SUBSPECIALTIES

* Neurology (Rx riluzole)
* Pulmonary (PFTs, Rx O2, BiPaP, CPAP, NIV, vent)
* Gastroenterology (PEG tube)
* Interventional Radiology (PEG Tube)
* Home Based Primary Care Program (HBPC)
* Homemaker/Home health Aid program (HHA)
* ENT (trach)
* Respiratory Therapy (supportive equipment)
COMMUNITY RESOURCES/REFERRALS

- ALS Association (caregiver support groups, family support groups, resource and referral, education and awareness, fund raising)
- Private Duty Home Care (overnight care)
- Community Nursing Home (respite care, hospice care, skilled nursing)
COMMUNITY RESOURCES/REFERRALS

- Long Term Acute Care (long-term ventilator care)
- Veteran Service Organizations (PVA, DAV)
- State Veteran Service Officers
- Social Security Administration
- State Medicaid programs (Home and Community Based Services, Long-term care Medicaid)
VHA Handbook Draft 1107.01 Directs that Veterans and their caregivers must have a single ALS health care point-of-contact to facilitate support and appropriate services and notes that the SCI Social Workers and Nurse Practitioners may be the best suited for this role.
Nurse Practitioner

- Combines rehabilitation and palliative care services
- Follow-up appointments, Telephone follow-up
- Coordination of Services
- Symptom and Medical Case Management
- Instilling hope
CASE MANAGEMENT

Licensed Clinical Social Worker

• Caregiver resources and education
  • VA Caregiver Support Program
  • ALS Association
• Advance Directives
• Community Resources
  • Community ADA transportation services
  • Social Security Administration
  • State Medicaid Program
  • Homecare
  • Community long term care
• VA Benefits
  • Referral to Veterans Service Organizations
SURVEY OF CURRENT STATE OF VA ALS SYSTEM OF CARE
VA’s 23 Spinal Cord Injury Centers were surveyed from April 2013 to August 2013.

SCI Centers’ Social Work and Nurse Case Managers were surveyed and asked about ALS care provided to Veterans in their centers.
Survey was conducted using Survey Monkey via email.

Survey was conducted in two steps.

1. First survey was sent out in April 2013 to SCI Center Social Workers/Program Coordinators. That data was collected and analyzed in July 2013.

2. Second survey was sent out in July 2013 to SCI Center Nurse Case Managers. That data was collected and analyzed in August 2013.

3. Results of the two surveys were combined. We will discuss these results of the combined survey here.
Survey Questionnaire

1. Does your SCI Program treat Veterans with ALS?
2. Does your facility provide inpatient services to Veteran with ALS?
3. Does your program provide outpatient services to Veterans with ALS?
4. If your center does not provide care to Veterans with ALS, please select the reason for this. Select as many as apply.
   a. We have a separate ALS clinic.
   b. We do not have access to Neurology.
   c. We do not have access to Pulmonology.
   d. We do not have ventilator beds/units.
   e. There are no facilities in our community with ventilator beds/units.
   f. We do not have access to adequate homecare programs for Veterans with ALS.
5. Please check the services your facility/program provides to veterans with ALS.

- a. Specialized wheelchairs (wheelchair clinic)
- b. Vehicle adaptations
- c. Respiratory therapy
- d. Home health services
- e. Home tube-feeding program
- f. Home respiratory therapy
- g. Respite care-in home/inpatient
- h. Caregiver support programs
- i. Adaptive equipment
- j. Assistive technology
- k. Speech therapy/swallow evaluation
6. Please check what subspecialty services your VA facility provides to ALS veterans.

a. We have a separate ALS clinic
b. Dietary services and support
c. ENT
d. Gastroenterology
e. Neurology
f. Palliative Care
g. Pulmonary
h. Ventilator beds/units
i. Other
7. Please check the case management services provided to veterans with ALS once they have been diagnosed
   a. clinical social work
   b. neurology
   c. palliative care
   d. primary care
   e. Home Based Primary Care
   f. Spinal Cord Injury/Disorder Provider
   g. Out patient ALS team
   h. other (please specify)
8. Please check the community programs to which you refer veterans with ALS.
   a. Veteran Service Organizations
   b. State Veterans Service Officers
   c. ALS Association
   d. Muscular Dystrophy Association
   e. Community Nursing Home
   f. Long-term acute care facilities
   g. Inpatient hospice
9. Do you have an ALS Association Chapter in your community?
SURVEY RESULTS
RESPONSE RATE

RESPONDENTS

![Pie chart showing response rate]

- **Responded**: 48%
- **Did not respond**: 52%

0% 0%
Does your SCI Program treat Veterans with ALS?

- Yes: 73%
- No: 27%
Does your facility provide inpatient services to Veterans with ALS?

- 73% Yes
- 27% No
Does your facility provide outpatient services to Veteran with ALS?

Response

- 73% YES
- 27% NO
Services your program provides to Veterans with ALS

- Specialized Wheelchairs
- Vehicle Adaptations
- Respiratory Therapy
- Home Health Services
- Home Tube Feeding Program
- Home Respiratory Program
- Respite Care-in home/inpatient
- Caregiver Support
- Adaptive Equipment
- Assistive Technology
- Speech Therapy/Swallow
We have a separate ALS clinic

Subspecialty services your VA facility provides to Veterans with ALS.

- Other
- Ventilator beds/units
- Pulmonology
- Palliative Care
- Neurology
- Gastroenterology
- ENT
- Dietary Service
- We have a separate ALS clinic
Case management services provided to Veterans with ALS once diagnosed

- We have a separate ALS Clinic
- Dietary Services
- ENT
- Gastroenterology
- Neurology
- Palliative Care
- Pulmonology
- Ventilator Beds/Units
- Other
Community programs to which you refer Veterans with ALS

- Inpatient Hospice
- LTAC
- Community Nursing Home
- Muscular Dystrophy Association
- ALS Association
- State Veterans Services Officers
- Veteran Service Organizations
Do you have an ALS chapter in your community?
Eleven out of 23 SCI Centers (48%) responded to the survey between April 2013 and August 2013.

Of the eleven facilities that responded, eight out of the eleven SCI Centers provide outpatient/inpatient ALS care.

Three of the eleven (27%) offer no ALS care, inpatient nor outpatient. The survey asked those who do not provide ALS care the reason for this. Two of the respondents did not answer this question, the third responded, “I don’t know”.

Survey Summary
While the eight facilities are doing well in offering wheelchairs, equipment and pulmonary services, home care services including home health, home RT, home tube feeding, and caregiver support appear to be limited.
The investigators of this study hypothesize that lack of rehabilitation goals and rehab potential may in part explain why some SCI Centers do not provide ALS care.

Of the SCI Centers that do provide ALS care, there are limited resources for home based services which may increase care burden on inpatient/outpatient services provided by the center.
The VA is uniquely equipped to provide the highest quality interdisciplinary care in our communities.

• Interdisciplinary clinics reduce the burden of multiple outpatient appointments.
• Interdisciplinary clinics improve coordination of care and case management services.
Home services including HBPC, home health care, home RT and ventilators, home palliative care/hospice, in-home respite care and caregiver support are essential as more and more Veterans and families will opt to receive in home care until the end of life.

For the complex ALS patient, services and care provided in the home will probably be found to less expensive and will contribute to a higher quality of life over time.
CLINICAL CASE PRESENTATION AND OUTCOME
Case: Mr. C

- 48 y.o. previously healthy male diagnosed with ALS in April 2006.
- Support system: Spouse, brother, daughter, son, parents. All assist with caring for veteran in the home.
- Symptoms which lead to diagnosis: uncontrolled laughing/crying, neck weakness, problems with speech.
- Seen twice in interdisciplinary clinic before becoming bed-bound
How SCI team helped Mr. C: Pseudobulbar affect, uncontrollable laughing and crying.

- Psychologist assessed for depression and PTSD. Veteran denied symptoms of depression and PTSD.
- Veteran and wife were not troubled by emotional lability and Veteran did not feel the need for anti-depressant medication (SSRI).
How the SCI team helped Mr. C: Loss of trunk control, neck weakness, loss of mobility.

- Wheelchair team provided customized power wheelchair with head rest in 2008.
- Social Worker and Occupational Therapist referred to charitable community organization “Homebuilders” who installed ramps prior to Veterans’ 100%SC rating.
- SHA grant provided for more extensive modifications within the home after Veterans’ 100%SC rating.
Case: Mr. C

How the SCI team helped Mr. C: Communication

• Speech therapist and assistive technology team evaluated and provided a Dynavox Eye Gaze system for communication in 2007.
• Unfortunately, Veteran is no longer able to use device due to progression of ALS, fatigue and limited endurance.
Case: Mr. C

How the SCI team helped Mr. C: loss of pulmonary and respiratory function:

- Evaluated by pulmonologist in chest clinic.
- Provided with trach and home ventilator in 2007 (Kaiser).
- Provided with home respiratory therapist.
- Provided with home nebulizer and suctioning.
- Wife and brother were trained on operation and function of home ventilator system.
- Home oxygen put into place.
Case: Mr. C

How SCI team helped Mr. C: dysphagia and weight loss
- Gastroenterology placed feeding tube 2007 (Kaiser).
- Home tube-feeding program with registered dietician implemented to monitor Veteran’s home tube feeding, train wife and family on tube-feeding, monitor weight loss and nutritional needs.
How SCI team helped Mr. C: Caregiver Support

- Social Worker assessed and assured Veteran and wife were maximizing home health program (HHA).
- Social Worker provided information on private duty homecare agencies in the community which could provide overnight care 2-3 days per week.
- Nurse Practitioner referred Veteran to the Home Based Primary Care (HBPC) and Palliative Care Program.
Veteran has lived at home with family, home health care, and home ventilator for seven years. Veteran is approaching end of life.

- HBPC and Palliative Care are now providing in home services.
- Social worker: clarifying advance directives. Veteran and wife have now made the decision not to treat infections with antibiotics.
- Social Worker: assisting Veteran and wife with options for long-term care in a community nursing home which provides ventilator care. This is a limited care option at this time. Only two in Colorado.
- Wife and family are weighing options for Veteran’s end of life care.
STRENGTHS:

* Interdisciplinary team
* Collaboration with subspecialty clinics
* HBPC relieving case management stress of team
* Team member Board Member of ALS Association
* Time-sensitive care coordination, dedication to case management and provision of equipment and services
S.W.O.T Analysis

WEAKNESSES:

* Denver VA Neurology will diagnosis & prescribe riluzole otherwise refers via fee basis to University Neurology specializing in ALS
* Routine telephone, telemedicine, or clinic time not allotted
* Need for pharmacy presence
* Need for specialty care for sialorrhea & botox per Handbook
* Telehealth request submitted but no initiation of services as yet
S.W.O.T Analysis

**OPPORTUNITIES:**

* ALS Systems of Care Procedures Handbook Draft has been created, final version TBA

* Rocky Mountain ALS Association willing to participate in VA ALS clinic

* Specialty PACT team possible

**THREATS:**

* No formal ALS clinic established

* Unknown timeline and plan for implementation
The Denver VA SCI/D team has been providing an interdisciplinary team approach to care for ALS longer than any other program in the community.

Care coordination with other specialties and subspecialties is essential in order to provide full spectrum of ALS care to Veterans.

Time-sensitive care coordination and full time dedication to case management, and caregiver support, Veterans’ care needs can be met in the home with little to no utilization of institutionalized care.
Outpatient Care Management of Veterans with ALS: Summary

- Much has been accomplished to provide Veterans with ALS the medically necessary services from the existing interdisciplinary SCI/D team.
- Expansion of the current program can go from meeting basic needs to providing excellent care when the Handbook 1107.7 is finalized and implemented into all VISNs.
Hope is the last thing that dies with me
Sherman Gillums
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