

Making the best of ALS: A VA Model of Care

Elizabeth Auld, PA-C
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I have no financial interest or relationships to disclose

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Hooray for PVA!!!

Learning Objectives

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

- A. Describe multidisciplinary care for persons with ALS;
- B. Use the ALS FRS to follow the disease progression and determine appropriate interventions
- C. Explain some of the unique challenges ALS care poses to the VA

Presentation Goals

- Keep you awake
- Get you on board
- Illustrate the extent of the task
- Show you how we've combined SCI and Neurology to do what we both do best
- Give you the important questions and some tools
- Peek into the future

Hard act to follow

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Goals of ALS Care

Similar to SCI and MS:

- Provide the best care
- Maximize quality of life
- Support to veteran and family

But more:

- Rapid progression
- Inevitably fatal
- Quality of death

VA ALS Clinic: Coordinated Care throughout the Disease Course

- **Medical/Physical**

- Initial diagnosis, prognosis, medications
- Ongoing
 - Symptom management
 - Prevention of complications
 - Rehab and Prosthetics for function and safety

- **Benefits**

- Establishing
- Increasing

- **Supportive: veteran and family**

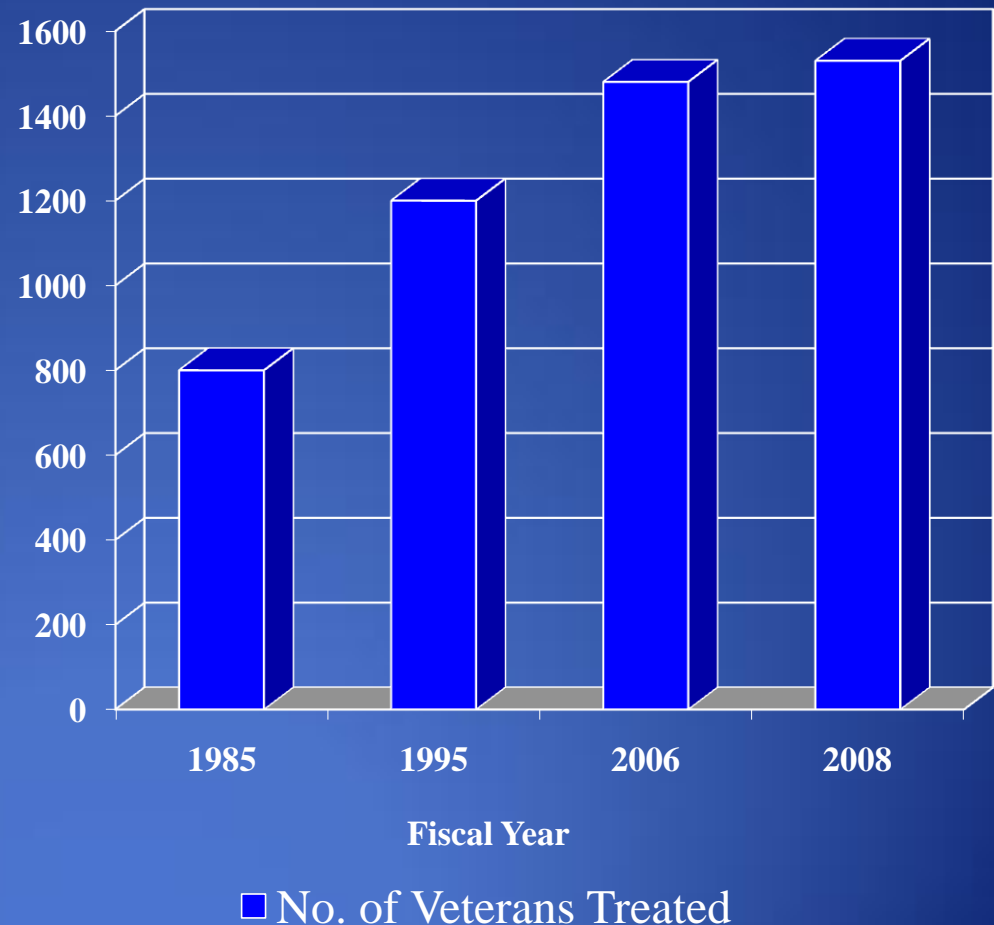
- Social
- Psychological
- End of Life discussions and support

The Challenges of ALS Care

- Complex, low incidence, progressive disease with physical and emotional components
- Few Experienced Health Care Providers: **EES**
- Need to couple primary and specialty care: **PACT**
- Veteran/Family need a “conductor”: **PACT**
- Progression of this disease is rapid – reduce delays in delivery of care/DME
- Veteran/Family need education and links to others with ALS
- **Number of veterans with ALS treated in VHA could double**

Prevalence of ALS Treated by VHA

- FY 2005-2008 VHA cared for 3581 veterans with ALS, average of 1521 vets per yr (42% rural 57% urban)
- VHA cares for ~42% of veterans with ALS

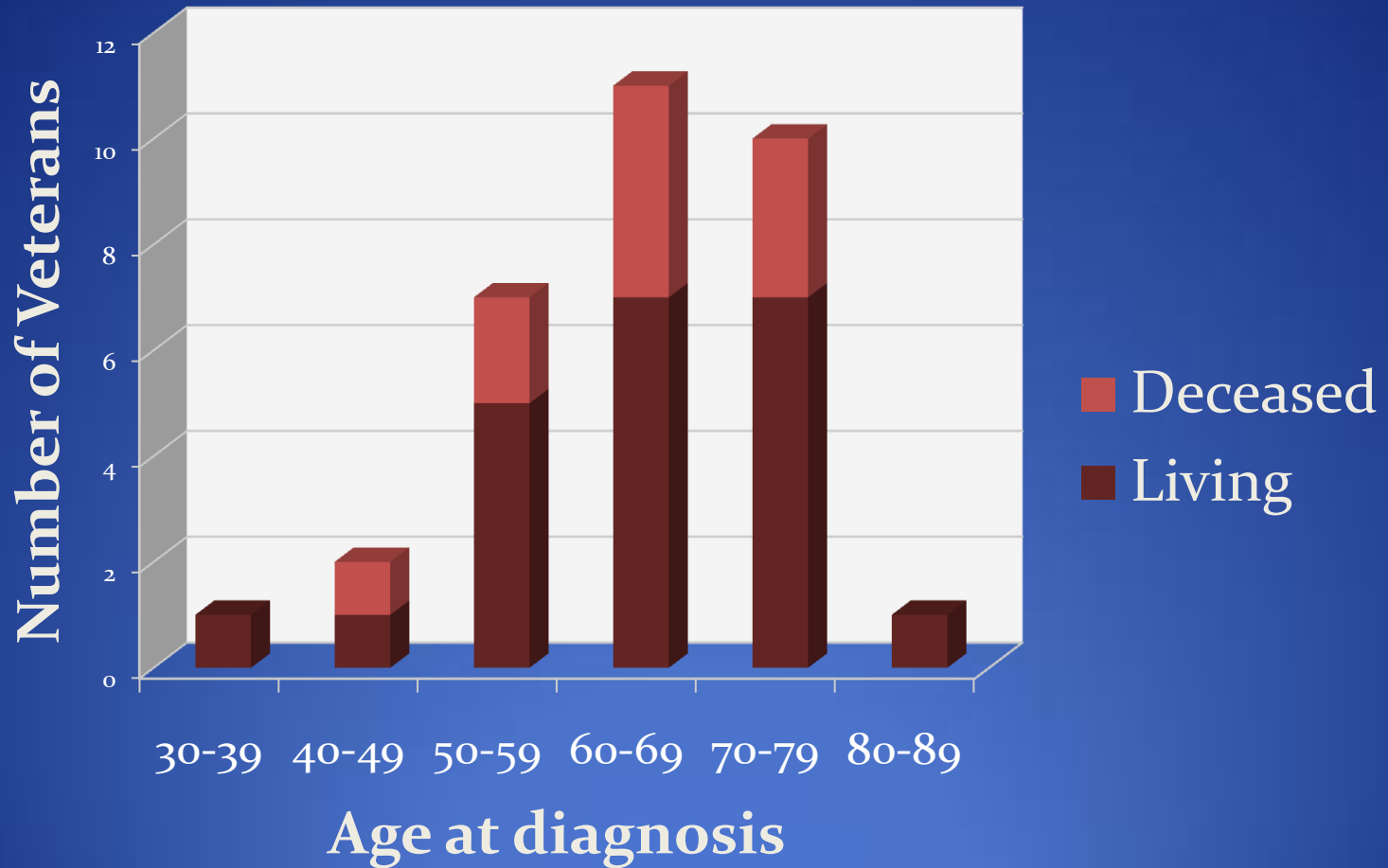


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VA Connecticut ALS Clinic, 2009-2011

(N = 32)



How we do it in VA Connecticut

LOCATION: SCI

CLINIC PARTICIPANTS:

Neurologist: Dr. Patwa

SCI Clinician: E. Auld, PA
Coordinator
Clinician

SCI Health Technician:

PT/OT:

Nurse Case Manager:

Social Work:

The Result: Neuro + SCI = Specialty PACT

Clinic Visits

Pre-clinic planning

Vitals with weight

History (for new patients)

Patient and family questions, reports of symptoms, function, needs

Functional symptom review, use ALS FRS (ALS Functional Rating Scale) as guide

Other symptom review:

- Pain

- Sleep

- Depression

- Emotional & personality

- Memory

End of Life discussions

The Clinic visit, continued:

Motor exam by MD or PA

Rehab Assessment

Nurse Case Manager

SW

Other if needed: Speech, Psychology, Nutrition

Wrap-up with patient and family

Team wrap-up

CONSULTS:

Respiratory: Spirometry (or more if indicated) on clinic day

SLP: Swallowing evaluations and Augmentative Communication

Pulmonary: Pulmonary management issues

GI: PEG placement

Nutrition: Tube feeding

Palliative Care:

Psychology: on wish list

Wheelchair:

OTHER:

Clinic schedule: ½ day weekly, 2-3 patients

Designated clinic with SCI and Neurology Stop Codes

Multidisciplinary Note

Aid & Attendance if needed

ALS Interdisciplinary Note: Important Elements

Communication and coordination of care:

Family contact information: phones, e-mail

Service officer

VNA information

Private MDs

Riluzole discussed, started, lab monitoring

Functional/adaptive:

Layout of home, access

Equipment already in place

Plus the elements discussed above, symptoms, etc.

ALS Functional Rating Scale

DATE:

SCORE: (0-48):

FVC:

Speech:

- 4 - Normal speech
- 3 - Detectable speech disturbance
- 2 - Intelligible with repeating
- 1 - Speech combined with nonvocal communication
- 0 - Loss of useful speech

Salivation:

- 4 - Normal
- 3 - Slight but definite excess of saliva in mouth, may have nighttime drooling
- 2 - Moderately excessive saliva; may have minimal drooling
- 1 - Marked excess of saliva with some drooling
- 0 - Marked drooling; requires constant tissue or handkerchief

Swallowing:

- 4 - Normal eating habits
- 3 - Early eating problems-occasional choking
- 2 - Dietary consistency changes
- 1 - Needs supplemental tube feeding
- 0 - NPO (exclusively parenteral or enteral feeding)

Handwriting:

- 4 - Normal
- 3 - Slow or sloppy; all words legible
- 2 - Not all words are legible
- 1 - Able to grip pen but unable to write
- 0 - Unable to grip pen

Cutting Food:

- 4 - Normal
- 3 - Somewhat slow and clumsy, but no help needed
- 2 - Can cut most foods, although clumsy and slow; some help needed
- 1 - Food must be cut by someone, but can still feed slowly
- 0 - Needs to be fed or is fed by gastrostomy tube

Dressing and Hygiene:

- 4 - Normal function
- 3 - Independent and complete self-care with effort or decreased efficiency
- 2 - Intermittent assistance or substitute methods
- 1 - Needs attendant for self-care
- 0 - Total dependence

Walking:

- 4 - Normal
- 3 - Early ambulation difficulties
- 2 - Walks with assistance
- 1 - Non-ambulatory functional movement only
- 0 - No purposeful leg movement

Climbing stairs:

- 4 - Normal
- 3 - Slow
- 2 - Mild unsteadiness or fatigue
- 1 - Needs assistance
- 0 - Cannot do

Dyspnea:

- 4 - None
- 3 - Occurs when walking
- 2 - Occurs with one or more of the following: eating, bathing, dressing (ADL)
- 1 - Occurs at rest, difficulty breathing when either sitting or lying
- 0 - Significant difficulty, considering using mechanical respiratory support

Bed Mobility:

- 4 - Normal
- 3 - Somewhat slow and clumsy, but no help needed
- 2 - Can turn alone or adjust sheets, but with great difficulty
- 1 - Can initiate, but not turn or adjust sheets alone
- 0 - Dependent for bed mobility

Orthopnea:

- 4 - None
- 3 - Some difficult sleeping at night due to shortness of breath.
Does not routinely use more than two pillows
- 2 - Needs extra pillow in order to sleep (more than two)
- 1 - Can only sleep sitting up
- 0 - Unable to sleep

Respiratory insufficiency:

- 4 - None
- 3 - Intermittent use of BiPAP
- 2 - Continuous use of BiPAP during the night
- 1 - Continuous use of BiPAP during the night and day
- 0 - Invasive mechanical ventilation by intubation or tracheostomy

Issues to Resolve: For individual clinics and for the VA System

- Logistics, Time, Space, personnel, support
- Prosthetics rules
- Expensive equipment: recycle?
- Coding to maximize reimbursement
- Managing homebound patients
- Managing vent patients: where?
- Getting expertise to where it's needed: use tele?
- Sharing information and experience
- Ongoing education
- Research

Why we do what we do



“I'm all alone in my home now, (the first time in my life). Everything happened so quickly--the downhill spiral in four days. But, George was granted all his wishes--he died at home surrounded by his family, he never completely lost his ability to communicate. He insisted on buying me an early anniversary present (a new gas grill) and we had a wonderful steak dinner and he ate everything. He never had a feeding tube or anything else. George always had a smile on his face, never complained, and loved his family, home, and friends. We had 39 years of a beautiful marriage together”

It takes a few “champions” but VA
ALS care can be the best there is.

Obtaining CME Credit

- If you would like to receive CME credit for this activity, please visit:

<http://www.pesgce.com/PVAsummit2011/>

- This information can also be found in the Summit 2011 Program on page 8.

This time last year . . .

