PALLIATIVE CARE AND VETERANS WITH ALS: LIFE-CARE PLANNING AND DELIVERING EXCELLENT CARE

Tony Hilton RN, MSN, FNP, CRRN DrPH(c)
Kathleen A. Bixby, RN, MSN, CHPN
August 30, 2012
Disclosures

• This continuing education activity is managed and accredited by Professional Education Service Group. The information presented in this activity represents the opinion of the author(s) or faculty. Neither PESG, nor any accrediting organization endorses any commercial products displayed or mentioned in conjunction with this activity.

• No Commercial support was received for this activity.
Faculty Disclosures

• Tony Hilton, MSN, FNP, CRRN, DrPH has no financial interest or relationships to disclose.
• Kathleen A. Bixby, MSN, CHPN has no financial interest or relationships to disclose.
• Professional Education Services Group staff have no financial interest or relationships to disclose.
Learning Objectives:

At the conclusion of the program, participants will be able to:

1. Describe the principles and rationale of life-care planning for Veterans with ALS and their families.
2. Describe guidance necessary to help patients and their families make the tough choices of their life-care decisions utilizing case studies.
3. Highlight proposed recommendations for interdisciplinary practice and explore key opportunities for co-management of ALS care, including collaboration with community partners.
• This program will focus on the quality of life of the patient with ALS when “cure” is not available, and the best of “care” is needed.
• How to integrate principles of Life Care Planning, Palliative and Hospice Care throughout the lifespan of the ALS patient.
Today’s Overview

1. Familiarize yourself with principles of Palliative and ALS

2. Understand key elements to successful care planning

3. What are some next steps to consider
Working Toward Provider Competency

- Get Training
- Get Experienced
- Achieve Competency
The Journey – “when time is of the essence”

- Aggressive care
- Life care planning
- Palliative care
- End of life care decisions
- Hospice care
- Mentoring other families in crisis
Continuum of Care:

ALS a chronic condition that is progressive in nature

Mild → Moderate → Severe

Episodic care → Palliative Care Services → Hospice
Aggressive Care Perspectives

Pulling all the stops when there is a new diagnosis:

- Alternative Method Approaches
- All efforts to keep life going for the miracle event
- Full code etc.
Life Care Planning (LCP)

“A life care plan is a dynamic information case management tool. The tool promotes a comprehensive understanding of patient care management needs over a lifetime – an understanding shared by the patient, family and the interdisciplinary team.”
Components of Life Care Planning

- history
- physical limitations
- activities of daily living
- socio-economic status
- education and training
- vocational history
COMPONENTS OF LCP

• vocational options and alternatives pre and post onset
• occupation and earnings
• medical care/services required
• rationale for services
• costs for services
• anticipated length of time needed
COMPONENTS OF LCP

- potential complications
- leisure activities
- drugs and therapies
- equipment needed
- anticipated future medical care
Palliative Care

• Palliative care is a holistic approach to managing the advanced symptoms of ALS.

• Goals for care:
  ➢ Maximize the quality of life of patients and their families
  ➢ Relieve symptoms
  ➢ Provide emotional, psychological, and spiritual support
  ➢ Remove obstacles to a peaceful death
  ➢ Support the family through the bereavement process
  ➢ Assure patient centered care
  ➢ Honor Veteran preferences
Eight Domains of Palliative Care

- Structure and Processes
- Psychiatric
- Physical
- Social
- Spiritual
- Cultural
- Ethical and Legal
- Imminently Dying Patient

Derived from NCPQPC, 2009
Box 5 Common themes of palliative initiatives in amyotrophic lateral sclerosis care

- Requirement for a national framework and patient pathway
- Nomination of a single person to coordinate amyotrophic lateral sclerosis care in a given phase of the disease
- Multidisciplinary amyotrophic lateral sclerosis care (incorporating hospital and community based palliative care services)
- Formal cognitive testing prior to advance directives
- Early and local palliative care involvement
- Structured caregiver support (grief support, counselling, support groups, crisis management system)
- Qualitative and quantitative measurement scheme to assess benefits of palliative care interventions
- Need for development of international consensus guidelines for the palliative management of amyotrophic lateral sclerosis

Bede, P., et al. 2011
Interdisciplinary Team Approach

Inpatient and outpatient Home Care Teams **must** include the patient and family as a vital component of the planning team.
Team Structures and Approaches

- **Multidisciplinary**
  - Disciplines working parallel to each other with clear lines of authority, creating goals independently, overseen by a physician with minimal communication between each other.

- **Interdisciplinary**
  - Disciplines meet regularly in order to work collaboratively to make joint patient care goals and have skills across each others disciplines. Communication is at a higher quality of interaction and team performance overseen by a physician.  

  Korner, M., 2010
## Interdisciplinary Teams

### Outpatient Clinic Teams
- PCP and Specialty physicians
- Case Manager
- Clinic support staff
- LCSW
- Home Health Care
- Prosthetics
- Neuro palliative Rehabilitation Therapist, PT, OT, Speech
- Respiratory Therapist
- Dentist
- Neuropsychologist
- Dietician
- Pharmacist

### Inpatient Teams - Acute & CLC
- PCP and Specialty physicians
- Case Manager
- Clinic support staff
- LCSW
- Home Health Care
- Prosthetics
- Rehabilitation Therapist, PT, OT, Speech
- Respiratory Therapist
- Dietician
- Clinical Psychologist
- Pharmacist
- Other: Volunteers/Pet Therapy
ALS (AMYOTROPHIC LATERAL SCLEROSIS)
Process of Care
Diagnosis to End-of-Life

Veteran diagnosed with ALS

Veteran agrees to treatment

Veteran declines care at this time

Veteran returns home

Re-evaluation when Veteran needs treatment

The IPQC (Interdisciplinary Plan of Care) team meets to discuss the plan of care and address questions and concerns post diagnosis

Clinical Social Worker completes a Mental Health Assessment & Psychosocial Assessment with 30 days

Veteran and Caregiver advise regarding challenges and needs

Engage veteran in treatment planning process after IDOC-100

Begin referral process to support group/psycho-educational classes

Clinical Social Worker assists with completion of an Advanced Directive when veteran is ready

Clinical Social Worker discusses assessment, drafts a treatment plan and discusses service options

Individualized Treatment Plan

Psychiatric Evaluation where indicated

Yes

Social Worker assists with setting individual benchmarks from diagnosis to end-of-life care

Commence Referrals and Linkage Agreements

Begin individual, family and group counseling

Re-Evaluation of Treatment Plan Quarterly to redefine goals as disease progresses

No

Glasses, or medications prescribed when needed

Revised resources, service options & scenarios ongoing

Admission to CNH, Rehabilitation facility, Regis Care in Placement or LTC

Home with DME, Vent Support, MFH (Medical Foster Home), HHHA, Caregiver Supportive Services

Palliative Care, Home Hospice or Inpatient
Dx: ALS

Clinic visits every 3 months
Early dysphagia detected
Nutritional education including PEG

Clinic visits every 3 months
Symptom progression

Monitor body weight
Dysphagia assessment instrument

Nutritional education including PEG

Monitor FVC or VC*

FVC* >50%
Low risk for PEG
PEG accepted
Oral intake as tolerated

FVC* 30-50%
Moderate risk
Anesthesia evaluation
Experienced gastroenterologist
Enteral nutrition via PEG as needed

FVC* <30%
High risk
PEG declined
Palliative IV hydration
Palliative NG feeding

*Forced vital capacity (FVC) or vital capacity (VC) can be used. VC may be more accurate in patients with bulbar dysfunction.

For example, Colorado Dysphagia Disability Inventory, bulbar questions in the ALS Functional Rating Scale, or other instrument.

Dx = diagnosis; PEG = percutaneous endoscopic gastrostomy.

Miller, R. G., et al. 1999
Dx: ALS

Respiratory symptoms or FVC < 50%

Noninvasive ventilation counseling

Noninvasive ventilation declined or not tolerated

Symptomatic care
Counsel about terminal phase
Hospice referral

Palliative care

Invasive ventilation declined

Institute noninvasive ventilation

Discuss treatment options (tracheostomy ventilation, etc.) and terminal phase

Invasive ventilation accepted

Discuss withdrawal conditions

Invasive Ventilation withdrawn

Invasive Ventilation withdrawn

Invasive Ventilation

Miller, R G. , et al. 1999
## Interdisciplinary Teams

### Home Care Team
- PCP
- Case Manager
- Home Health Care visit staff
- LCSW
- Shift family/agency caregiver support
- Prosthetics
- Home Health Therapist
- Respiratory Therapist
- Pharmacist

### Palliative/Hospice Teams
- PCP and Specialty physicians
- Case Manager
- Clinic support staff
- LCSW
- Home Health Care
- Prosthetics
- Palliative care practitioners
- Respiratory Therapist
- Pharmacist
- Volunteers/Pet Therapy
Symptom Management

- Dyspnea
- Pain
- Communication verbally
- Swallow
- Immobility

- Sialorrhea
- Dysphagia
- Anxiety
- Insomnia
- Mood disorders
- Cognitive changes
Goals for care will be SMART

• **Specific**
• **Measurable**
• **Achievable**
• **Realistic**
• **Timely**
Assessment and Goal Planning

- Medical/Health care status
- Family resources
- Financial resources
- Home physical environment
- Transportation
- Equipment
- Medications/treatments
- Community resources
- Leisure/vocational interests
- Advance Directives/POLST

- Optimize medical care
- Identify home caregivers
- Work within financial restraints/benefits
- Adapt home environment
- Facilitate transportation ongoing care
- Determine medical equipment/supplies
- Identify community resources
- Facilitate leisure/vocational interests
Goals: Simplify Care Needs

Simplify and minimize complex care needs without sacrificing optimal care e.g.

- Lowest Oxygen requirements (maintain $PO_2$-$PCO_2$ levels within safe range)
- Ventilation settings
- Adequate nutritional intake
- Medication/treatment regimen

This will make room to enjoy the simple things in life.
Home Care Environmental Needs for Advancing Care

- Power wheelchairs- hand, sip/puff/chin control.
- Eye gaze computers, voice amplifiers
- Environmental control units
- Enteral feedings and supplies
- Communication devices and supplies
- Ventilatory support devices and supplies
- Home modifications
- Transport van
- Hospital bed, shower chairs, bedside commode

Identify equipment upon initial procurement that will continue to meet advancing care to end of life e.g. ventilator, power chair, communication devices
Access to Health Care

• Distance from Medical Care/Support
  – VA Medical Center
  – Interdisciplinary Team clinics

• Home care providers experts in ALS care
  – Home Health Agency
  – Respiratory Home Care providers
Funding/Resources

- VA Benefits
- Medicaid/Medicare
- Private Insurance
- Support Services
  - ALS Association
  - MDA Association
  - PVA
  - Aid and Attendance
  - Bowel Bladder care
  - Caregiver support
Home Environment

- Home evaluation
  - Physical Environment
    - Safety
    - Accessibility
    - Adaptations/remodel
  - Transportation system
    - Accessibility
    - Safety
    - Dependability
Community Activities/Resources

- Church going activities
- Entertainment parks
- Restaurants
- Travel to nearby by towns
- Air or long distance travel
- Cruises
- International travel
- Other
Predicting the Future???
Coping with Loss
Box 1 Suggested triggers for hospice referral by the Amyotrophic Lateral Sclerosis Peer Workgroup

1. Forced vital capacity (FVC): 60% predicted (or rapid decline in FVC (more than 20%) over 2–3 months) or
2. Clinical signs or clinical symptoms of respiratory insufficiency or
3. Respiratory weakness requiring non-invasive positive pressure ventilation or
4. Nutritional decline requiring enteral feeding or
5. Severe pain or psychosocial distress requiring intensive palliative care interventions (including opioid medication) or
6. Rapidly progressive paralysis (over 2–3 months) in two body regions

Bede, P., et al. 2011
Box 3 Triggers of end of life discussions in amyotrophic lateral sclerosis

1. The patient opens the discussion—for end of life information and/or interventions (elicited or spontaneous, verbal or non-verbal).
2. The presence of severe psychological, social or spiritual distress or suffering
3. The presence of pain requiring high dosages of analgesic medications
4. The presence of dysphagia requiring feeding tube
5. The presence of dyspnoea, symptoms of hypoventilation or a forced vital capacity of 50% or less
6. Loss of function in two body regions (regions include bulbar, arms and legs)
Ethical and Caregiver Issues

• Ethical Issues
  – Withholding / withdrawal of life support
  – Defining quality of life
  – Resource allocation

• Psychosocial Issues
  – Burnout
  – Family disruption
  – Caregiver burden
Keys to Patient Success

• Early diagnosis and treatment
• Opportunity of caregiver respite services to minimize burnout
• Education and information to make informed decisions and maintain skill competencies
• Early intervention to discuss life care planning
• Interdisciplinary team approach to care
• Access to a qualified POC case manager from diagnosis through end of life.
• Access to caregiver respite services.
Keys to Caregiver Success

• Obtain as much knowledge and skills about ALS
• Realize you cannot manage the patient alone
• Bring in key partners/disciplines early into the treatment process
• Collaborate with experts in ALS care
• Listen carefully to the patient and their families as you plan their care.
• Have access to a family primary caregiver responsible for patient care in the home that is willing and capable to assume the role.
ALS Interdisciplinary Team

Experiential learning curve
Quality of Life Attributes

• PHYSICAL DIMENSIONS - ADL, mobility, symptoms

• PSYCHOLOGIC DIMENSIONS - depression, hope

• SOCIETAL DIMENSIONS - relationships, activities

• COGNITIVE DIMENSIONS - memory, judgment

• SPIRITUAL DIMENSIONS - peace about life and death

• LIFE SATISFACTION PERCEPTIONS
Quality of Life Perspectives

- Quality of Life as defined by:
  - Patient
  - Caregiver
  - Healthcare professional
Quality of Life Outcomes (QOL)

- Data analysis revealed:
- QOL was highly subjective and individual
Factors influencing QOL were internal and external to the patient including:

- Psychosocial adaptation
- Complexity of care
- Access to care
- Community activities
- Level of independence
- Depth of relationships

Hilton, T., et al. 2002
QUALITY OF LIFE
Case Studies
ICU Case Study

- 67 year old ALS patient ventilator dependent for 3 months in the ICU
- Prior to admission stated wish for no life support
- Consistently requested for 2 months the ventilator be discontinued
- Family hesitantly requested that patient’s wish be followed
CASE STUDY #1

- 34 YEAR OLD MALE WITH ALS FOR 8 YEARS ON VENTILATION
- EXPERIENCED WORSENING OF PULMONARY INFECTIONS
- FEARS DROWNING - NOT DEPRESSED
- REQUEST DC OF VENT

ANALYSIS
- WHEN THE BURDENS OF RX EXCEED THE BENEFITS IT IS ETHICALLY PERMISSIBLE TO FOLLOW REQUEST

OUTCOME - WORSENING OF SYMPTONS
- MD PROVIDED IV SEDATION AND DC VENTILATION
CASE STUDY #2

- 51 YEAR OLD ALS PATIENT ON HOME VENTILATION
- REQUEST DC OF VENTILATION
- ANALYSIS
  - THERE IS NO MORAL OBLIGAITON TO ACCEPT LIFE-SUSTAINING TECHNOLOGY
  - COMPETENT PATIENT’S HAVE THE RIGHT TO ACCEPT/DECLINE LIFE SUSTAINING RX
- OUTCOME
  - SAID HIS GOODBYES FOR SEVERAL DAYS
  - ON DAY OF CHOOSING SEDATION PROVIDED WITH HOSPICE SUPPORT
  - FAMILY SUPPORTED PATIENT’S DECISION
Ethical Analysis Principles

- There is no moral or legal difference between withholding or withdrawal of treatment.
- Decisions for or against life sustaining treatment require that patient be fully informed.
- It is ethically permissible, if not obligatory, to respect competent patient request.
Outcomes

- Date and time set to discontinue life support
- Patient sedated with IV meds
- Family present as per patient request
- Staff provided supportive therapy
- Ventilator discontinued by MD
Putting the pieces back together again
Pearls to consider...

• Interdisciplinary clinics that provide care to inpatients and outpatients per facility ALS team hospital policy has improved quality of life for the patients.

• ALS patients have more complex issues to address because of choices for life prolonging therapies.

• Practitioners generally avoid and fear discussing advance care planning and wait too long when the patient would like to talk about it.

• Practitioners should feel free to introduce the topic sooner than later with patients and their families.
Pearls to consider...

• Choosing life sustaining treatment like ventilatory support is often perceived as physical, emotional, financial burdensome care to family members.
• Informed consent is the most crucial component in life care planning since it results in life changing decisions to families.
• Informed consent is best provided by practitioners who have first hand experience with implications and patients talking to other ALS patients who have made those decisions.
• In our experience, patients and families are more likely choose life sustaining technology, like invasive ventilation and its related care, when funding is available.
Pearls to consider...

• Learning and understanding the care requirements of patients with ALS provides greater comfort and competency in care.

• Patients who decline life sustaining technology like long term mechanical ventilation may be referred to hospice as they progress into respiratory failure.

• Hospice care funding is usually very limited for those who choose ventilation and generally not an option.

• Patients who choose to withhold or withdraw life sustaining treatment is usually because they have lost hope and meaning in continued life.
Pearls to consider...

• Optimal management of the ALS patient requires a palliative care approach from diagnosis to end of life with emphasis on quality of life, dignity and autonomy.
• ALS centers of excellence are a critical component of successful care in coordination with home telehealth services.
• Nurse practitioners with strong case management background are ideal ALS PCP’s
• Poor quality of life is related to hopelessness and lack of social support.
• It is ideal that the interdisciplinary team are the same team members in outpatient and inpatient care settings to facilitate continuity and seamless care.
Pearls to consider...

• Given this choice, patients with ALS will want to remain as comfortable as possible and can change their minds midstream to implement life sustaining treatments.

• A well-managed interdisciplinary plan of care can often minimize preventable ED and acute care visits by early interventions in the home and is most cost effective as a life care plan.

• Intensive educational training, informed consent procedures and adaptations to non invasive/invasive ventilation, facilitates improved outcomes.

• Early detection and treatment are complemented by care systems that adopt an interdisciplinary approach to care. Advance care planning insures attention to goals of care and individual preferences which can inform effective life care planning, promoting both quantity and quality of life.
Thank You
References

ALS and VHA Handbook, 2012 publication and distribution pending

A study released by the Institute of Medicine on November 10th 2006, *Amyotrophic Lateral Sclerosis in Veterans: Review of the Scientific Literature*


QUESTIONS AND COMMENTS?
Obtaining CME/CE Credit

If you would like to receive continuing education credit for this activity, please visit:

www.pesgce.com/PVA2012