Applying the Promise/Domain Model to ALS Care:
An Interactive Learning Session

PVA Summit 2013
August 27, 2013
Disclosures

The presenters of this session have nothing to disclose.

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Commercial Support was not received for this activity.
CHALLENGE: Increasing need for quality care

Today, around the world, nearly 450,000 people are living with ALS. VHA has provided care for > 3600 Veterans with ALS over the past 4 years. This does not include Veterans with ALS receiving care in the private sector.
Statement of Purpose

‘Crosswalk’ between two frameworks of quality care delivery:

Quality of Life (QOL) Domains of Care
Seven Promises for a Better System of Care
Explore care coordination, collaboration, and compassionate engagement of Veterans living with ALS, their families, and their caregivers – facilitating choices that focus on goals of care and relationship-centered satisfaction and quality care outcomes.
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<th>Learning Goals</th>
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<td>1. Provide at least three illustrations of how the Promise/Domain ‘crosswalk framework’ can influence choices for ALS Care.</td>
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<td>2. Identify two situations in which choices directed at supporting the physical domain may change when the other domains are considered.</td>
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<td>3. Discuss the implications of not considering the psychological, social, and spiritual domains in advance care planning – exploring goals of care and making choices.</td>
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<td>4. Using case study presentations, identify care options at different stages of disease progression that reflect attention to quality of life and Veteran/family goals and preferences.</td>
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Jot down the most immediate thoughts and words that come to mind when you learn someone has been diagnosed with ALS…

You learn about a newly diagnosed Veteran, scheduled for an initial visit during next week’s clinic – write down any additional thoughts or words that come to mind…

You learn about a colleague who has just been diagnosed with ALS – add any additional thoughts or words…
- Partner with your fellow attendees – briefly introduce yourselves and your role in healthcare...

- Share the thoughts and reactions that came to mind when thinking about individuals diagnosed with ALS...

- Consider whether or not your thoughts and feelings changed as you became more ‘familiar’ with the individual diagnosed with ALS → anyone → Veteran → colleague…
Symptom Management

- Immobility
- Dyspnea
- Communication
- Dysphagia
  - Swallow
  - Sialorrhea
- Pain
- Anxiety
- Insomnia
- Mood disorders
- Cognitive changes
QOL and Person-Centered Care

Physical
- Functional ability
- Strength/fatigue
- Sleep & rest
- Pain/symptoms

Social
- Financial
- Caregiver status
- Roles & relationships
- Affection/sexual function
- Appearance

Psychological
- Cognition/attention
- Happiness
- Enjoyment/leisure
- Depression/anxiety
- Fear/distress

Spiritual
- Value/dignity
- Meaning/hope
- Suffering/distress
- Spirituality/religiosity
- Transcendence

Adapted from Betty Ferrell and Marcia Grant, City of Hope, 2007
Consider **making promises** to patients and families, promises about how a patient dying in the health care system can expect – and therefore demand – to be treated…

Making Promises…

#1 – Good medical treatment: You will have the best of medical treatment, aiming to prevent exacerbations, improve function and survival, and ensure comfort.

#2 – Never overwhelmed by symptoms: You will never have to endure overwhelming pain, shortness of breath, or other symptoms.

#3 – Continuity, coordination, and comprehensiveness: Your care will be continuous, comprehensive, and coordinated.
#4 – Well-prepared, no surprises: You and your family will be prepared for everything that is likely to happen in the course of your illness.

#5 – Customized care, reflecting your preferences: Your wishes will be sought and respected and, whenever possible, followed.
#6 – Use of patient and family resources (financial, emotional, and practical): We will help the patient and family to consider their personal and financial resources, and we will respect their choices about the use of their resources.

#7 – Make the best of every day: We will do all we can to see that you and your family will have the opportunity to make the best of every day.
Tom's Dream: A World Without ALS (A Love Story)

https://www.youtube.com/watch?v=8AVsuKrpmI4
Reconnect with your “new IDT”…

Take the next several minutes to collectively brainstorm your thoughts and feelings following a glimpse at Tom’s diagnosis with ALS…What surprised you, what moved you, what inspired you…

Now consider Tom’s experience of ALS using the QOL and Person-Centered Care domains along with the 7 promises for best care possible…

How many elements were involved in defining ‘hope’ as he/they journeyed “ONE WAY,” his way…
QOL and Person-Centered Care

Physical
- Functional ability
- Strength/fatigue
- Sleep & rest
- Pain/symptoms

Social
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Adapted from Betty Ferrell and Marcia Grant, City of Hope, 2007
#1 – Good medical treatment: You will have the best of medical treatment, aiming to prevent exacerbations, improve function and survival, and ensure comfort.
**QUALITY of LIFE ➔ ↓ SEVEN PROMISES**

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### #1 – Good medical treatment: You will have the best of medical treatment, aiming to prevent exacerbations, improve function and survival, and ensure comfort.

- Patients will be offered proven diagnosis and treatment strategies to prevent exacerbations and enhance QOL, as well as to delay disease progression and death.
- Medical interventions will be in accord with best available standards of medical practice, and evidence-based when possible.

| ? Riluzole ➔ delay in progression | Finances ➔ physician x 2 years ➔ ? outstanding school loans ➔ ? insurance coverage ➔ ? copayments and/or out of pocket expenses ➔ ? support from medical community, i.e. charity/benefit fundraisers ➔ private-pay and/or insurance-paid services and equipment | Remained |
| ? swallowing ➔ Sialorrhea | Immobility ➔ motorized wheelchair |
| ? swallowing ➔ feeding tube | Speech/communication ➔ ? voice banking, augmented communication equipment |
| | Anxiety, Insomnia, Mood disorders ➔ ? role of supportive medications |

### Finances

- Patients will be offered proven diagnosis and treatment strategies to prevent exacerbations and enhance QOL, as well as to delay disease progression and death.
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### Remained

- “He decided to go skiing and sailing and he did a lot of things one last time…”
  
  – Tom

### “There is hope everywhere. Grab it and run with it.”

  – Tom
#2 – Never overwhelmed by symptoms:
You will never have to endure overwhelming pain, shortness of breath, or other symptoms.
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#2 – Never overwhelmed by symptoms: You will never have to endure overwhelming pain, shortness of breath, or other symptoms.

- Symptoms will be anticipated and prevented when possible, evaluated and addressed promptly, and controlled effectively.
- Severe symptoms – such as shortness of breath – will be treated as emergencies.
- Sedation will be used when necessary to relieve intractable symptoms near the end of life.

## PHYSICAL

- Use of non-invasive ventilation (NIV) (BiPAP) before trach and invasive ventilation → informed consent and discussion about pros and cons → planned intubation vs. emergency

  - Recommend early use and 'practicing' with BiPAP during daytime hours if having difficulty using at night

  - Transition from use at night to intermittent use during daytime hours to palliative fatigue, weakness, and/or the work of breathing

  - Increasing sx and work of breathing → increased use of BiPAP → increased likelihood of NIV dependence without secured airway

  - Impact on personal care, i.e. showers

## SOCIAL

Caregiver responsibilities/burden significant (24/7) with NIV dependence and vent support

- Vent care @ home with trained caregivers vs. in VA contracted vent-care facility → proximity of facility to home of caregiver/NOK

## PSYCHOLOGICAL

- “In med school, Tom always said ALS is the worst disease, and he referred to the disease as ‘the beast’”

  - Fear/anxiety about what to expect as respiratory failure progresses – details about “the end”

  - Portable BiPAP with battery pack enhances mobility and increased access to leisure activities

## SPIRITUAL

- “He wanted to be DNR once the respiratory was effected”

- Lack evidence specific to QOL at time of death with NIV in use → continued functioning of machine in absence of life vs. use of palliative sedation?
#3 – Continuity, coordination, and comprehensiveness: Your care will be continuous, comprehensive, and coordinated.
### QUALITY of LIFE ➞ ↓ SEVEN PROMISES

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#### #3 – Continuity, coordination, and comprehensiveness:

Your care will be continuous, comprehensive, and coordinated.

- Patients and families can count on having certain professionals to rely upon at all times.
- Patients and families can count on an appropriate and timely response to their needs.
- Transitions between services, settings, and personnel are minimized in number and made to work smoothly.

**Functional ability continues to decline despite interventions, i.e. use of BiPAP and ventilator.**

- Multi/interdisciplinary approach to care is more effective and less burdensome ➞ fatigue is a predictable symptom with extended clinic visits.

**Multiple Healthcare Providers:**
- Primary Care Provider
- Neurologist (Community)
- Pulmonologist (Community)
- ALS and MDA/ALS Clinics
- VA Caregivers
  - PCP
  - Specialty Clinics
  - ALS Clinic
  - Home Based Primary Care (HBPC)
- Home Health Care Agencies
  - H/HHA
  - Skilled care
  - DME providers
  - Care/Case/Disease Management Coordinators
  - Palliative Care
  - Hospice

**Need for back-up ventilatory support equipment to support potential equipment failure with NIV/Vent dependence ➞ feasibility of obtaining back-up equipment ➞ link to EMS.**

**Need for generator to support equipment function during power failure.**

- Interventions/equipment to support symptom management, i.e. suction and cough assist ➞ use depends on success of caregiver education, instruction, and commitment to use.

**Increased cost of in-home care if NIV/vent dependent ➞ BiPAP requires skilled care (LPN/RN) vs. HHA according to state nurse practice acts.**

**Continuous use of NIV precludes access to long term inpatient skilled nursing care in the absence of a secured airway.**

**Veterans w/ ALS – 100% SC ➞ C&P monthly income ➞ as functional loss increases with disease progression, additional levels of allowance (Aide and Attendance) available to support home care needs – Aide and Attendance determinations require physical assessment – travel often presents additional challenge.**

**Home hospice team’s availability to respond to shortness of breath “as an emergency” ➞ access to continuous ‘crisis’ care to actively and effectively manage respiratory failure at home.**

**Veterans w/ ALS – 100% SC ➞ C&P monthly income ➞ as functional loss increases with disease progression, additional levels of allowance (Aide and Attendance) available to support home care needs – Aide and Attendance determinations require physical assessment – travel often presents additional challenge.**

**Experience of support group members can circumvent anxiety and inform advance care planning and decision making.**

**Distress r/t potential equipment failure**

**Distress r/t potential power failure**

**Depression/anxiety/distress r/t caregiver burden and cost of additional caregivers**

**Patient/family/caregiver response to multiple providers in and out of home ➞ challenges routine and predictability ➞ may negatively impact willingness to access additional support.**

**Increasing evidence supporting distress and suffering of caregivers ➞ need for evidence based approaches to support primary caregivers.**
#4 – Well-prepared, no surprises: You and your family will be prepared for everything that is likely to happen in the course of your illness.
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#4 – Well prepared, no surprises: You and your family will be prepared for everything that is likely to happen in the course of your illness.
- Patients and families will come to know what to expect, and what is expected of them, as the illness worsens.
- Patients and families will receive supplies and training needed to handle predictable events.

- Review changes between visits with directed discussion about disease progression with appropriate anticipatory planning (visits typically scheduled every 3 months)
- Advance care planning discussions and documentation to support same, i.e. State Authorized Portable Orders to honor resuscitative preferences, especially if hospice care not yet involved
- f/u as needed prior to next scheduled visit with change or worsening symptoms
- Education/instruction to promote energy conservation
- Education/instruction to support new equipment/procedures

- Access to, and financial coverage for BiPAP/Vent, suction equipment, cough-assist machine, battery pack, back up BiPAP/Vent, generator
- Complex care – challenge locating affordable, reliable, and competent caregivers → consider shared caregiving to enhance continuity especially if paid caregiver unexpectedly unavailable
- Anticipate alteration in physical intimacy r/t respiratory insufficiency and reliance on supportive NIV/Vent
- Initial and ongoing education to support understanding of diagnosis and disease progression to avert unnecessary fear associated with respiratory insufficiency and failure
- Review recommended palliative interventions, supportive equipment, and behavioral changes and modifications that will be available as the disease progresses
- Assist patient/family in exploring and developing support network and coping skills, to include access to local support groups

- Incorporate dialogue about meaning, hope, distress, etc. into regular visits

26 November 2013
#5 – Customized care, reflecting your preferences: Your wishes will be sought and respected and, whenever possible, followed.
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- Patients and families will come to know the alternatives for services and will expect to make choices that matter.
- Patients will never receive treatments they refuse.

It is usually possible for patients to die at home if they so desire.

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Advance care planning
- Introduce alternatives early
- Identify preferences
- Document preferences

Financial burden associated with intensified caregiving needs as disease progresses – can be complicated by need for caregiver to work in order to maintain household income and insurance benefits

Role changes with regard to parenting and pre-existing caregiving responsibilities for other family members (i.e. parent with dementia)

Attention to goals and aspirations in light of dx with creative problem solving to support plans to pursue same

Early discussions and documentation of goals and preferences important in light of potential alteration in cognitive function associated with frontal temporal dementia

“Tom truly learned how to adjust to living with ALS – looked at it as a game, “I have love, and you (ALS) can’t take that away”

Incorporate dialogue about meaning, hope, distress, etc. into regular visits

26 November 2013
#6 – Use of patient and family resources (financial, emotional, and practical): We will help the patient and family to consider their personal and financial resources, and we will respect their choices about the use of their resources.
## QUALITY of LIFE

### SEVEN PROMISES

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### #6 – Use of patient and family resources (financial, emotional, and practical):

- We will help the patient and family to consider their personal and financial resources, and we will respect their choices about the use of their resources.
  - Patients and families will be aware of services available in their community and the costs of those services.
  - Family caregivers’ concerns will be discussed and addressed, and respite and home care aide care will be considered as part of the care plan when appropriate.

- Explore patient/family interest, and consider referral to nearest ALS/MDA interdisciplinary clinic with attention to financial and practical impact of travel, etc.
- Ask if individual with ALS has served in the military and provide information necessary for Veterans to pursue access to financial and healthcare benefits
- Support Veteran’s interest/desire to access healthcare services through local VA facility – collaborative care encouraged, especially as Veterans may be involved in clinical trials

- Level of involvement (financial, emotional, and practical) of family members is as unique as individuals diagnosed with ALS
- Provider/Team awareness of the cost of care – recommendations offered along with suggestions regarding interviewing and selection of service providers
- Support groups offer credible and practical information about access to, and experience with, community resources – provide contact information for local support group(s)
- Utilize family meetings to address complex care planning among multiple providers and multiple caregivers

- Goal of honoring preferences complicated by:
  - Cognitive impairment
  - Depression/anxiety
  - Fear/distress
  - Marital discord
  - Unrealistic expectations of caregivers
  - Competing social, emotional, or financial demands on individual with ALS and/or the caregiver

- Explore and encourage spiritual resources to supplement financial, emotional, and practical resources
- Explore connectedness to faith community and/or elements of spirituality, including fostering and nurturing significant relationships

26 November 2013
#7 – Make the best of every day: We will do all we can to see that you and your family will have the opportunity to make the best of every day.
# QUALITY of LIFE – SEVEN PROMISES

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#7 – Make the best of every day: We will do all we can to see that you and your family will have the opportunity to make the best of every day.
- The patient is treated as a person, not a disease.
- The care team attends to the physical, psychological, social, and spiritual needs of patient and family.
- Families are supported before, during, and after the patient’s death.

Expect attention to personal ‘story’ and quality of living specific to physical symptoms related to ALS → symptom management with positive impact on quality of life.

Expect attention to personal ‘story’ and quality of living specific to changes in roles, relationships, and responsibilities associated with diagnosis and progression of ALS → support, education, instruction, and counseling with positive impact on quality of life.

Expect attention to personal ‘story’ and quality of living specific to happiness and enjoyment as well as experience of fear and distress → promote engagement in cognitively stimulating and leisure activities that have a positive impact on quality of life.

Expect attention to personal ‘story’ and quality of living specific to meaning in life, connectedness, and values and belief beyond self → acknowledge response to challenges and personal growth with positive impact on quality of life.
Seven Promises – What to expect, living with a serious illness through end-of-life:
✓ correct medical treatment
✓ minimal symptoms
✓ no gaps in care
✓ no surprises
✓ customized care
✓ attention to family role
✓ assistance as needed to live fully

QOL – Attend to physical, psychological, social, and spiritual domains of living to ensure quality care
Apply the Promise/QOL Domain ‘framework’ to another case

Explore patient/Veteran/family and interdisciplinary perspectives

Discuss and present promise/domain-specific thoughts, interventions, and recommendations
VIDEO: **So Much So Fast**

*So Much So Fast* documents 5 years in the life of Stephen Heywood, diagnosed at age 29 with the paralyzing neurodegenerative disease ALS (Lou Gehrig’s disease). Determined to live as well as possible, Stephen gets married, has a son, and rebuilds two houses. Stephen, his wife, Wendy, and friends and family share their observations of the world and Stephen’s disease as they explore the fragility of life…

*So Much So Fast.* Film by Steven Ascher and Jeanne Jordan
Film clip used with permission from West City Films @ www.westcityfilms.com
IDT’s collaboratively assess and explore “best care possible” in caring for Veterans with ALS

View clip from “So Much So Fast” with attention to the Quality of Life (QOL) domains and Seven Promises

‘Crosswalk’ across the QOL domains, identifying how a single promise was met, noting what could/should be considered, suggested, or offered…

Consider your responses as if Stephen is a Veteran…
#1 – Good medical treatment: You will have the best of medical treatment, aiming to prevent exacerbations, improve function and survival, and ensure comfort.

✓ Patients will be offered proven diagnosis and treatment strategies to prevent exacerbations and enhance quality of life, as well as to delay disease progression and death.

✓ Medical interventions will be in accord with best available standards of medical practice, evidence-based when possible.
#2 – Never overwhelmed by symptoms: You will never have to endure overwhelming pain, shortness of breath, or other symptoms.

- Symptoms will be anticipated and prevented when possible, evaluated and addressed promptly, and controlled effectively.
- Severe symptoms – such as shortness of breath – will be treated as emergencies.
- Sedation will be used when necessary to relieve intractable symptoms near end of life.
#3 – Continuity, coordination, and comprehensiveness: Your care will be continuous, comprehensive, and coordinated.

✓ Patients and families can count on having certain professionals to rely upon at all times.

✓ Patients and families can count on an appropriate and timely response to their needs.

✓ Transitions between services, settings, and personnel are minimized in number and made to work smoothly.
#4 – Well-prepared, no surprises: You and your family will be prepared for everything that is likely to happen in the course of your illness/

- Patients and families will come to know what to expect, and what is expected of them, as the illness worsens.
- Patients and families will receive supplies and training needed to handle predictable events.
#5 – Customized care, reflecting your preferences: Your wishes will be sought and respected and, whenever possible, followed.

✓ Veterans and families will come to know the alternatives for services and will expect to make choices that matter.

✓ Veterans will never receive treatments they refuse.

✓ It is usually possible for Veterans to die at home if they so desire.
#6 – Use of Veteran and family resources (financial, emotional, and practical): We will help the Veteran and family to consider their personal and financial resources, and we will respect their choices about the use of their resources.

- Veterans and families will be aware of services available in their community and the costs of those services.
- Family caregivers’ concerns will be discussed and addressed, and respite and home aide care will be considered as part of the care plan when appropriate.
#7 – Make the best of every day: We will do all we can to see that you and your family will have the opportunity to make the best of every day.

✓ The Veteran is treated as a person, not a disease.

✓ The care team attends to the physical, psychological, social, and spiritual needs of patient and family.

✓ Families are supported before, during, and after the Veteran’s death.
Seven Promises – What to expect, living with a serious illness through end-of-life:

- correct medical treatment
- minimal symptoms
- no gaps in care
- no surprises
- customized care
- attention to family role
- assistance as needed to live fully

QOL – Attend to physical, psychological, social, and spiritual domains of living to ensure quality care
Relationships...
THANK YOU for all you do!


