*Telephone: 866-970-7500 ext. 203*
*Website: www.hospiscript.com*
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*Telephone: 614-763-0036*
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*Email: info@midwestcarealliance.org*

# "Lunch & Learn" Seminar — Independent-Study Program

## Provided by HospiScript Services, LLC and the
## Midwest Center for Home, Hospice & Palliative Care Education
## Palliative Care and Hospice for Patients with ALS (01/2011) ● Expires 01/31/13

HospiScript Services and the Midwest Center for Home, Hospice & Palliative Care Education are pleased to announce that our very popular "*Lunch & Learn*" seminars are now available online as self study programs offering continuing educational (CE) credit. These learning modules are accessible to HospiScript clients via www.hospiscript.com and to OHPCO members via www.ohpco.org.

This recorded series has been available for quite some time, but did not offer the option of receiving continuing educational credit. We are delighted that in addition to offering excellent education in a format to be accessed at your convenience, we are now offering you and your staff members another source to assist you in meeting your CE requirements.

Each seminar (*beginning with 2009*) is available as an independent-study program and includes the documents needed to apply for CE credit within this handout. After listening to the seminar online, simply complete the CE Request Form which includes both an evaluation and post test. Once completed, submit it along with the processing fee of $10 to request credit. In order to qualify for credit, a minimum score of 70% must be achieved on the post test.

Please be advised that credit for CE purposes may only be awarded to each person once per seminar. It is the responsibility of the student to keep his or her personal records to avoid repeating a module. Periodical audit reviews will also be conducted to determine any violations.

We hope you will find this convenient new format helpful and effective!

**Disclosure Information:**
The planning committee has declared no conflict of interest. To resolve any conflict, the presenter has agreed to present information fairly and without bias, according to policy.
☒ Disclosure ☐ Nothing to Disclose
Discussion of off-label use of drugs.
No commercial support was received for this educational activity.

Midwest Center for Home, Hospice & Palliative Care Education (OH-248/4-01-12) is an approved provider of continuing nursing education by the Ohio Nurses Association (OBN-001-91), an accredited approver by the American Nurses Credentialing Center's Commission on Accreditation.
HospiScript Services LLC approved by California Board of Registered Nursing, Provider #14740 (9/30/12) for 1 contact hour.

# Online Independent-Study Program ● CE Request Form
# Palliative Care and Hospice for Patients with ALS (Jan. 2011)

**Requesting CE Credit For:** ☐ **Nursing CE**

**Upon submittal of the proper forms, this program offers 1 CE credit for nursing valid nationally (not valid for Iowa licenses).*

**Criteria for Successful Completion**: Listening to the audio seminar, submitting completed CE Request Form with processing fee, and achieving a minimum score of 70% on the post test.

**Expiration**: This program expires on January 31, 2013.

**Part I - Participant Information** *(please print legibly)*

| | |
|---|---|
| Date Completed: | |
| Name: | |
| Employer: | |
| Occupation/Credentials: *(RN, LPN, SW/C)* | |
| Complete Mailing Address: *(Street, City, State, Zip)* | |
| Phone: | |
| Email Certificate To: | |

**Part II - Evaluation**

Were the following objectives met?

1. Describe the natural history of ALS. ☐ YES ☐ NO
2. Discuss benefits and burdens of PEG tube and ventilatory support for patients with ALS. ☐ YES ☐ NO
3. Enumerate common physical symptoms and psychosocial/spiritual challenges in ALS. ☐ YES ☐ NO

This speaker demonstrated effective teaching on a scale of 5 (excellent) to 1 (poor):

Robert M. Taylor, MD: ☐ 5 ☐ 4 ☐ 3 ☐ 2 ☐ 1

Comments: ____________________

Questions for Speaker: ____________________

**Part III - Post Test**

1. PEG tube placement in ALS
   a. ☐ Reduces quality of life by making it impossible for patients to eat normally
   b. ☐ Invariably prolongs survival
   c. ☐ Eliminates the risk of aspiration
   d. ☐ Is safest and most beneficial if placed when respiratory status is relatively good
2. Most ALS Patients decline invasive mechanical ventilation ☐ TRUE ☐ FALSE
3. Pain does not occur in ALS ☐ TRUE ☐ FALSE
4. Pain does not occur in ALS
   a. ☐ 40%
   b. ☐ 60%
   c. ☐ 80%
   d. ☐ 100%
5. When an ALS patient who has become dependent on non-invasive ventilatory support decides to discontinue that support, Palliative Sedation is ethical if required for comfort ☐ TRUE ☐ FALSE
6. Length of time (IN MINUTES) to complete this self study: ____________

**Disclosure Information:**

Robert M. Taylor, MD ☐ Nothing to Disclose ☒ Disclosure

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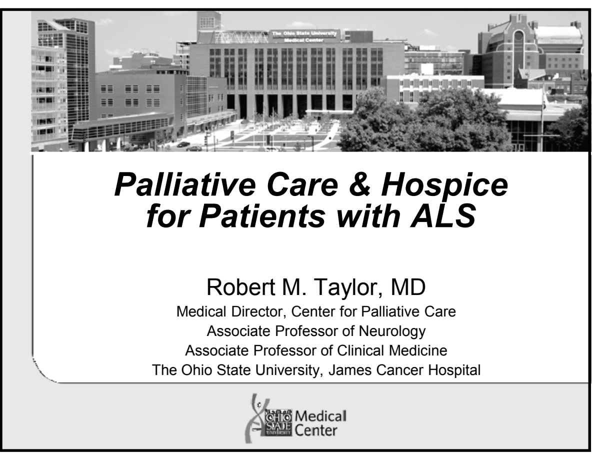
Send this original completed form and $10 processing fee to:

HospiScript Services, LLC, Attn: Mary Anne McDowell, 1460 Ann St., Montgomery, AL 36107



***Palliative Care & Hospice for Patients with ALS***

Robert M. Taylor, MD
Medical Director, Center for Palliative Care
Associate Professor of Neurology
Associate Professor of Clinical Medicine
The Ohio State University, James Cancer Hospital

The Ohio State University Medical Center

## Natural History of ALS

- Characterized by progressive weakness of all muscle groups
- Average survival from time of diagnosis is 2 to 5 years; HOWEVER
  - About 20% live more than 5 years
  - About 10% live more than 10 years
  - About 5% live more than 20 years

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## ALS characteristics

- Progressive weakness
- Preserved cognitive function is typical
  - Some exceptions
- Eventually dysphagia & respiratory failure
  - PEG may prolong survival & improve QOL
  - NIV &/or home MV usually prolong survival
  - Still, death from ALS complications is the rule
- Patients usually remain aware & competent
  - Fear of physical suffering is common

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## ALS Interdisciplinary Clinic

- Neurologist
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- Respiratory Therapist, Pulmonologist
- Social Worker, Mental Health Professional
- Patient Service Coordinator
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- Others

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## Symptoms of ALS

- Direct
  - Weakness, atrophy
  - Fasciculations
  - Cramps
  - Spasticity
  - Dysphagia
  - Dysarthria
  - Dyspnea
  - Pseudobulbar
- Indirect
  - Psychological
  - Sleep disturbances
  - Constipation
  - Drooling
  - Thick secretions
  - Pain
  - Symptoms of chronic hypoventilation

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## Chronic hypoventilation syndrome

- Daytime fatigue and sleepiness
- Concentration problems
- Disturbed sleep, nightmares, morning HA
- Tachypnea, dyspnea, phonation problems
- Reduced appetite, weight loss
- Recurrent or chronic URI
- Cyanosis, edema, tachycardia
- Use of auxiliary respiratory muscles

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## AAN Practice Parameters

- Respiratory management guidelines
  - Be vigilant for symptoms of hypoventilation and monitor respiratory function tests
  - Use NIV as initial therapy for symptomatic chronic hypoventilation and to prolong survival
  - When LT survival is goal, consider mechanical ventilation, fully informing patients and families
  - Patients have a right to refuse or discontinue any therapy, including NIV or LTMV
  - When withdrawing ventilatory support, use adequate opiates and anxiolytics/sedatives to relieve dyspnea and anxiety

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## Pain in ALS

- Pain in ALS appears to be more common than previously thought
  - Prevalence uncertain, but not uncommon
  - Multiple mechanisms
  - Effective treatment necessary for QOL
  - Opiates are safe and well-tolerated if used judiciously
    - Start at low doses and titrate cautiously
    - Also effective for dyspnea

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## Pain Medication Options

- Intensol medications (sublingual)
  - Morphine 20 mg/cc
  - Oxycodone 20 mg/cc
  - Lorazepam 2 mg/cc
  - Haloperidol 2 mg/cc
  - Avoids need for IV, IM, SC in most cases
- If patient has a PEG tube, can use for meds
- Topical meds useful for some patients
- IV or SC medications sometimes required

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## Pain Medication Options

- Adjuvants may be beneficial
  - Spasticity often exacerbates pain
    - Baclofen is often effective (20-80 mg/day)
    - Valium or other benzos may be effective (usual doses)
  - Neuropathic agents may provide benefit
    - Gabapentin and pregabalin are often beneficial
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## Caregiver Burden

- ALS patients
  - Often are unable to continue working within a short time of diagnosis (varies with SES)
  - Typically require progressively increasing assistance with ADLs
  - Frequently experience progressive difficulty with communication
- Caregivers are often required to work both for income and insurance
- Professional support and medical equipment are often very expensive

11

## ALS patient suffering & QOL

- 20% of patients rated suffering $\geq$4/6
- Suffering correlated with
  - Increasing pain
  - Poorer QOL
  - Greater hopelessness
  - Worsening functional status
  - Greater sense of being a burden to others
  - Depressive symptoms

12

## ALS patient suffering & QOL

- Suffering & QOL were strongly correlated
  - Suffering correlated more strongly with effects of the disease on body and psyche
  - QOL correlated more strongly with social factors
- Patient and caregiver ratings correlated better for patient suffering than QOL
  - Suffering may elicit greater empathic response from caregiver

13

## Advance Care Planning

- Consider natural history of ALS
- Predictable events and decisions should not become unanticipated crises
  - Feeding tube for dysphagia
  - NIV and MV for respiratory failure
  - Communication problems (common)
  - Cognitive impairment (rare)

14

## Advance Care Planning

- Ongoing process, not an event
  - Decisions may change over time
- Permits patient and family control
  - Advance Directives
    - Living Will
    - Durable Health Care Power of Attorney
  - Resuscitation status

15

## PEG Tube for Dysphagia

- PEG in ALS
  - Improves nutrition
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  - Survival increased only in patients where PEG inserted early
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17

## PEG Tube for Dysphagia

- PEG tube AAN guidelines
  - Indicated for patients with symptomatic dysphagia and should be placed soon after symptom onset
  - Should be placed before FVC < 50% for optimal safety and efficacy

18

## Respiratory Support

- NIV has become increasingly common & may
  - Improve dyspnea
  - Improve sleep and energy levels
  - Prolong survival
- Patients may become dependent on NIV
- MV is an option chosen rarely (about 2%)
  - Burdens frequently outweigh benefits
  - Caregiver and economic burdens may be significant

19

## Triggers for EOL Discussion

(Mitsimoto et al 2005)

- Patient or family request
- Severe psychological, social, or spiritual distress or suffering
- Pain requiring high doses of analgesic medications
- Dysphagia requiring a feeding tube
- Dyspnea or symptoms of hypoventilation or FVC < 50% predicted
- Loss of function in 2 body regions

20

## Ethical Considerations

- Right to forego Life-Prolonging Treatment (LPT) is well-established
  - Endorsed by US courts, AAN and other professional societies
- Important to anticipate the future
  - Ongoing discussion is critical
  - Involve families and significant others
    - POA for HC essential if nontraditional family
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## Ethical Considerations

- It is unlikely that appropriate doses of opiates or sedatives shorten survival in patients dying of respiratory failure
- However, even if they do, their use is still legal and ethical
  - Benefits/burden analysis
    - Relief of suffering takes precedence over a few more hours or days of survival
  - Principle of double effect (next slide)

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## Principle of Double Effect

- An action that may have both good and bad effects is ethical if
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## Discontinuing Respiratory Support

- Patients discontinuing long-term NIV or MV will typically have minimal capacity for functional respiration
  - Usually most comfortable if heavily sedated
    - IV medications usually required
  - Will not shorten survival significantly
  - Discuss with patient and family explicitly
  - $O_2$ supplementation may prolong the dying process and thereby increase discomfort

24

## Hospice for ALS

- Provides support for patients and families
- Services provided by Hospice are appropriate for anyone with a complex advanced illness
- Would be beneficial to most patients with ALS much earlier in the disease
  - Medicare guidelines restrict availability of Hospice to those with a life expectancy of 6 months or less
  - Prognostication is challenging - do not delay referral till patient is actively dying

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## Hospice for ALS

- No clear-cut criteria for 6 mo prognosis but any of the following indications is appropriate:
  - FVC < 50% or decrease 20% in 3 mos
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## Hospice for ALS

- Insurance coverage & services provided
  - Covered by Medicare & Medicaid
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  - Regular visits by nurses and aides
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  - Equipment, comfort meds usually covered
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- What is a good death?
    - Comfort, lack of physical suffering
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## Conclusions

- Advance care planning should be routine for all patients with ALS
  - Include families if possible
  - Encourage formal advance directives
- Hospice and Palliative Care is appropriate for many patients with ALS
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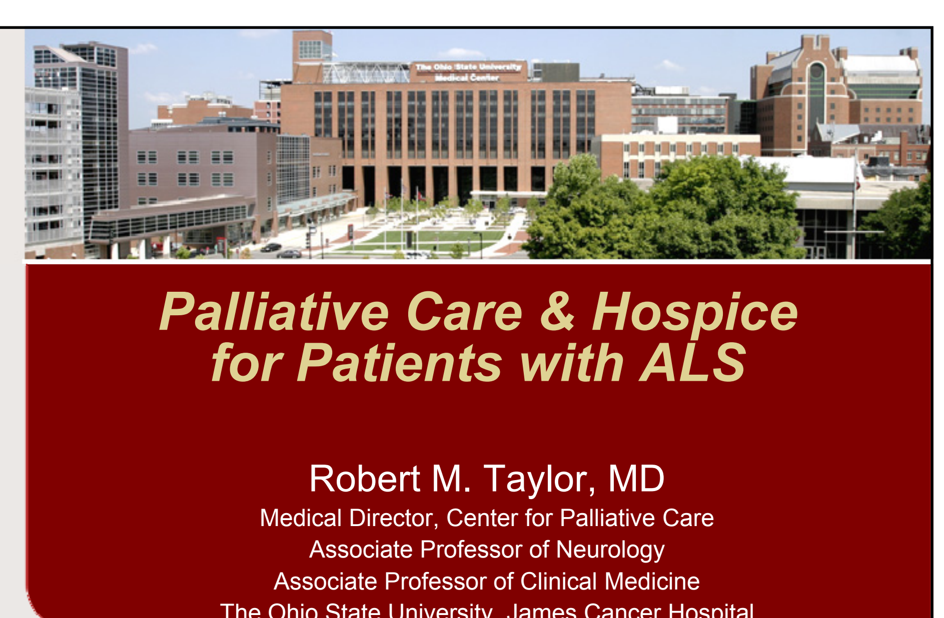


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