Integrating Palliative Care into American ALS practice

Karen L. Cross, MD, AAHPM
Hospice & Palliative Carecenter
Winston-Salem, NC
<table>
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<th>Palliative Med Program</th>
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<td>Other Developed Countries</td>
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<td>Developing Countries</td>
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What does ALS look like?
Symptoms commonly seen in ALS

- Pain
- Dyspnea
- Anxiety
- Pseudobulbar effect
- Sialorrhea
- Weakness
- Edema
- Itching
- Skin breakdown/decubitus ulcers
- Infections
- Confusion about disease modifying therapy
  - PEG and total ventilation
- Muscle spasm
- Headache
- Depression
- Fatigue
- Dysphagia
- Weight loss
- Dysarthria
- Constipation
- Financial issues
- Family stress and burnout
- Caregiving needs
QUESTION

Do ALS patients/families need palliative care?
Yes!
The *Emerging* American Style of Incorporating Palliative Care into ALS/NMD
The American Style of Incorporating Palliative Care into ALS/NMD
Why “emerging” in the U.S.?

Hospice & Palliative Medicine is a young field
Why “emerging” in the U.S?

Lack of knowledge about H&P Medicine:

healthcare professionals
patients and families
Why “emerging” in the U.S?

Myths
Why “emerging” in the U.S?

Outright Lies
Palliative Care & ALS
“Emerging” → “Merged”

Step #1
Find a champion within your ALS team or department
“Emerging” → “Merged”

Step # 2
Partner with a local hospice & palliative care organization
Do ALS patients need palliative care?
Living with a serious illness can be challenging in so many ways. You may be dealing with pain and other uncomfortable symptoms, fearful about your future or concerned about how your loved ones are coping with your illness. If you are visiting this website because you or a loved one is seriously ill, we hope the information and guidance you find here will be helpful.

We are doctors who specialize in palliative medicine, a type of care that prevents and alleviates suffering. We have special training and expertise in relieving pain and other symptoms caused by your illness or your medical treatments. We can provide guidance as you make decisions about your care, and we work as part of a team that helps you and your loved ones find the emotional or spiritual support you need.

Palliative care is for people of any age, and at any stage in an illness, whether that illness is curable, chronic or life-threatening. Palliative medicine specialists work alongside and support your other doctors, who may be providing treatments to cure or reverse the course of your illness. If a cure is out of reach, we can provide palliative medicine through a hospice program, helping you focus on quality time with your loved ones.

With a focus on comfort and compassion, we are committed to helping you and your loved ones meet the challenges of your illness and live each day as fully as possible.
“Emerging” → “Merged”

Step # 3
Invite the Palliative Medicine provider to join your interdisciplinary team
“Emerging” → “Merged”

Step # 4

Have Patience
Emerging” → “Merged”

Step # 5
Give the palliative care professional the really hard cases
Literature

New England Journal of Medicine article 8/19/10
Early Palliative Care for Patients with Metastatic Non-Small-Cell-Cell Lung Cancer

Temel JS, Greer JA, Muzikanssk A. Early Palliative Care for Patients with Metastatic Non-Small-Cell-Lung Cancer. N. Engl J Med 2010; 363: 733-742
Literature

Palliative Care in Amyotrophic Lateral Sclerosis, Parkinson’s Disease, and Multiple Sclerosis

Elman LB, Houghton DJ, Wu GF, et. al  Palliative Care in Amyotrophic Lateral Sclerosis, Parkinson’s Disease, and Multiple Sclerosis JI Palliative medicine 2007;10(2):433-457
My Contact Information

Karen.cross@hospicecarecenter.org
Questions?