



# Integrating Palliative Care into American ALS practice

Karen L. Cross, MD, AAHPM  
Hospice & Palliative Carecenter  
Winston-Salem, NC

# survey

	Palliative Med Program
United States	
Other Developed Countries	
Developing Countries	



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

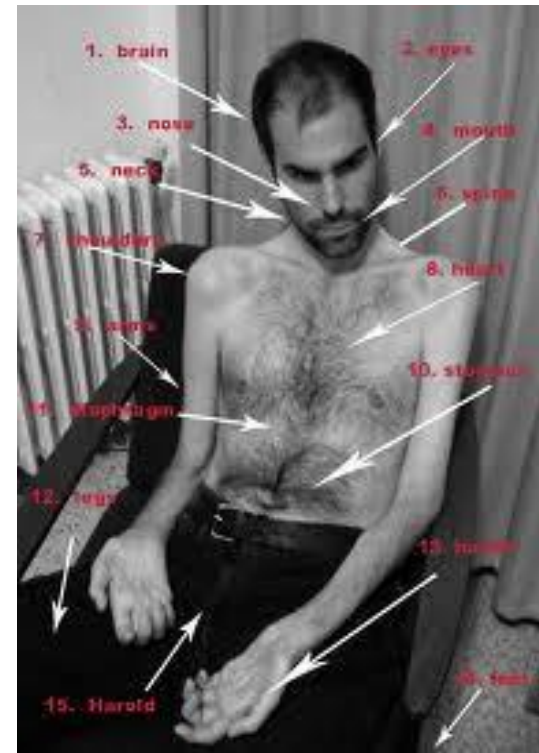
Dysarthria

Constipation

Financial issues

Family stress and burnout

Caregiving needs





# QUESTION

Do ALS patients/families need palliative care?



**Yes!**

US





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



# National Hospice & Palliative Care Organization



Welcome

**MEMBER LOGIN**

Login ID:

Password:

**SUBMIT**

[Forgot Password?](#)

[Create an Account](#)

Join NHPCO

[Find a Provider](#)

[What's New](#)

[Education and Conferences](#)

[Member/Vendor Guide](#)

[News Room](#)

[Informacion En Espanol](#)

**QUICK LINKS**

[Hospice Advocacy Regulatory Center InfoCenter](#)

*Advancing care at the end of life...*

-  Professional Resources
-  Quality Partners
-  About NHPCO
-  Learn About End-of-Life Care
-  Make a Contribution

## NHPCO Breaking News

-  **Early Bird Registration**  
- now available for next April's MLC!
-  **Record 1.56 Million Served**  
- new Facts & Figures report released.
-  **October NewsLine**  
- available now.
-  **Education Needs Assessment Survey**  
- for all members except Executive Directors/CEOs/COOs.

Learn more about:

-  **National Hospice Foundation**  
*Committed to compassionate care at the end of life*
-  **FHSSA**  
*Compassion has no borders*
- 
- 
- 

# American Academy of Hospice & Palliative Medicine



American Academy of  
Hospice and Palliative Medicine

Physicians Caring for Patients with Serious Illness



[ABOUT](#) [ADVOCATE](#) [JOIN](#) [PRACTICE](#) [TRAIN](#) [CERTIFY](#) [LEARN](#) [SHOP](#)

SEARCH



[MEMBER LOGIN](#)

-  [JOBS](#)
-  [TAKE ACTION](#)
-  [READ OUR JOURNAL](#)
- 

FEBRUARY 16-19, 2011  
VANCOUVER

# American Academy of Hospice & Palliative Medicine



## PalliativeDoctors

Compassionate care at any stage of an illness

ADJUST TEXT SIZE AAAA

SEARCH THIS SITE

SHARE & BOOKMARK

Home

What is Palliative Care?

What does a Palliative Doctor Do?

Benefits of Palliative care

When to Seek Hospice Care

For Caregivers

Patient Stories

In the News

Resources

FAQs

Find a Palliative Doctor

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.




**We work alongside and support your other doctors**

“Emerging” → “Merged”

## Step # 3

Invite the Palliative Medicine provider to join your interdisciplinary team

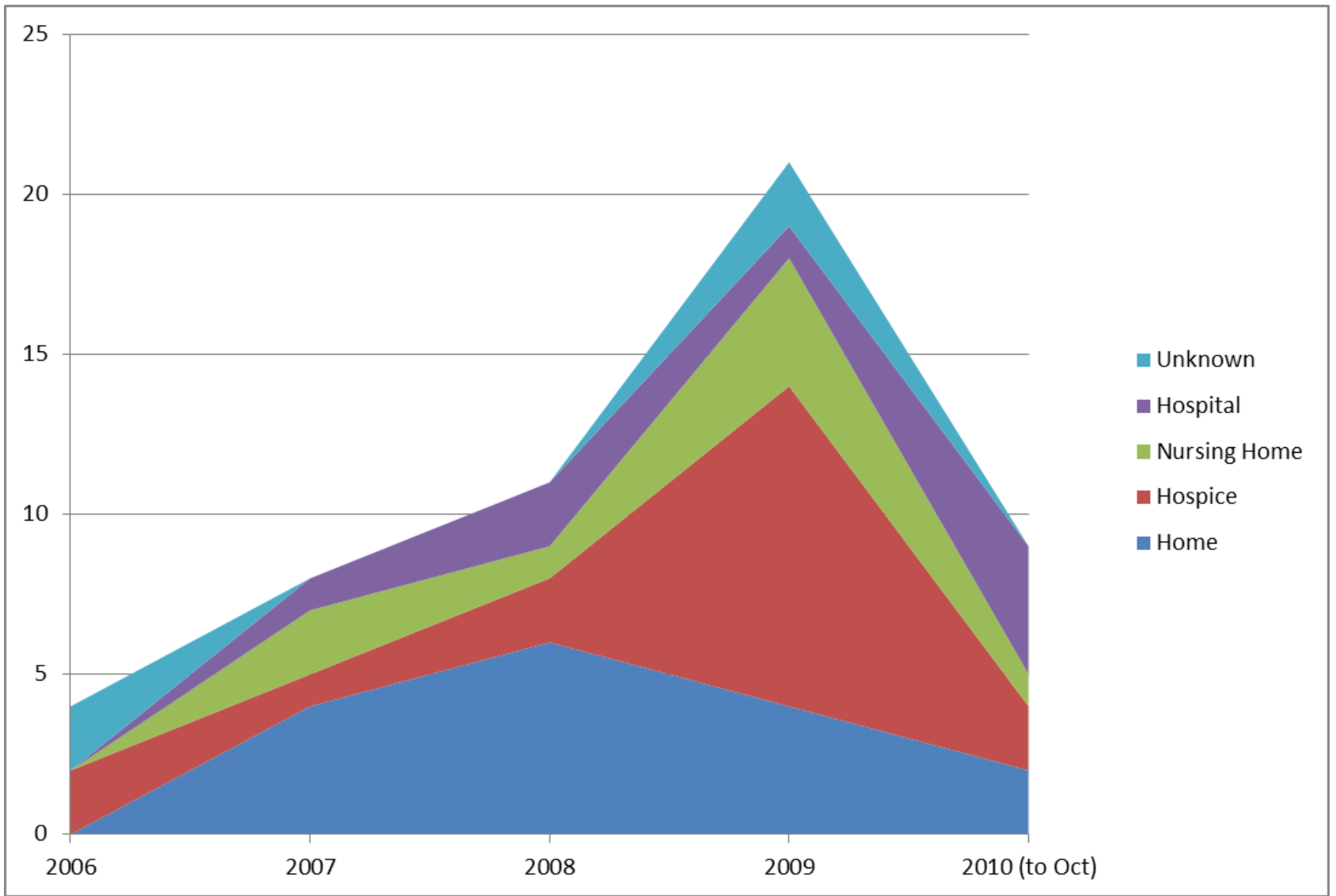





“Emerging” → “Merged”

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-Lung Cancer

Temel JS, Greer JA, Muzikansk 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 J Palliative medicine 2007;10(2):433-  
457



# My Contact Information

[Karen.cross@hospicecarecenter.org](mailto:Karen.cross@hospicecarecenter.org)



Questions?