



Means to a Better End: A Report on Dying in America Today
**Messages for Hospice and
Palliative Care Organizations and Providers**

Theme: Hospice/palliative care meeting needs better than ever

Message: Hospice and palliative care are meeting the needs of terminally ill patients and their families in greater numbers and more far-reaching ways than ever before.

Supporting Points:

- Caring for more types of illnesses, notably Alzheimer's, heart failure and COPD.
- We are breaking through the barriers that prevented some cultures from experiencing optimal end of life care.
- We are expanding our spiritual care offerings to recognize and celebrate the diverse spiritual needs of Americans.

Theme: Earlier and more wide-spread use of hospice/palliative care would benefit patient and family

Message: The rankings reflect the use of end-of-life care, not the quality. Top notch, quality end of life care is available, but more terminally ill patients could benefit from the pain management and social and spiritual care that hospice offers and both patient and family would benefit from earlier use.

Theme: Hope rankings will spark public discussion – because more is needed

Message: We hope the state ranking will spark public discussion on end of life care because few Americans know their options or how they're funded and fewer still have discussed their desires with their physician and family.

Supporting Points:

- Few Americans know that Medicare Hospice Benefit covers all aspects of end of life care, including prescription drugs for pain management, care in a home or inpatient setting and bereavement care for the family.

Questions and Answers

General End of Life Care

Address any general questions about end of life care with any or all of the three messages: While hospice/palliative care is meeting needs better than ever, earlier and more widespread use of hospice/palliative care would benefit terminally ill patients and families. More public discussion is clearly needed.

Example:

Do you think this is an accurate reflection of end of life care in the United States?

We think it's a rough yardstick and the rankings really reflect use of end of life care more than quality. Hospice and palliative care are meeting the needs of terminally patient in more far-reaching ways than ever before, but earlier care would benefit patients and families. People don't know about the benefits of hospice and they're not being referred early enough by their physician. More public discussion is clearly needed.

Poor Rankings

Respond that the study reflects use rather than quality, then bridge immediately to the positive hospice/palliative care message and examples.

Example:

- ***The overall report portrays a landscape of mediocrity. How do you feel about that?***

We think the report reflects the use of end of life care rather than quality. Top-notch, quality end of life care is available, but more terminally ill patients could benefit from the pain management and social and spiritual care that hospice offers and both patient and family would benefit from earlier use. If this state ranking stimulates a public discussion that educates professionals and consumers to the benefits of hospice care then it will certainly have served its purpose.

Study Methodology

Decline specific comment on methodology and bridge to ... "what's important is that the ranking spark much needed public discussion."

Example:

- ***What do you think of the methodology?***

Methodology can always be argued and this is no exception. The findings should be viewed as a rough yardstick, not a perfect measuring tool. What's important is that the ranking spark much needed public discussion. For instance, it's important that Americans know about the Medicare Hospice Benefit and use it when appropriate, not for "brink of death" care.

- ***What do you think of the criteria? Do they accurately measure the quality of end of life care?***

We think they speak more to use of end of life care than the quality. Top notch, quality end of life care is available, but more terminally ill patients could benefit from the pain

management and social and spiritual care that hospice offers and both patient and family would benefit from earlier use.

Credentials of Panel

Compliment the credentials of the panel, then bridge to... “trying to spark public discussion.”

Example:

- ***What was your (hospice) role in the development of this rating system?***
Last Acts brought together a group of highly qualified individuals to develop the criteria and methodology. It was a difficult task and even they don't consider it to be an accurate measuring tool. They were trying to spark public discussion and felt they couldn't wait for perfect methodology or flawless data.

State and Program Specific Data

Regardless of your specific state ranking, use this as an opportunity to say that while hospice/palliative care is meeting the needs of terminally ill patient better than ever, earlier use would benefit patient and family

- ***What does this ranking say about the end of life care in our state?***
It says more about the use of end-of-life care than the quality of that care. The truth is that top notch end of life care is available in most communities in America, but more terminally ill patients could benefit from its use and both patient and family could benefit from earlier use. Here at xxx we're doing more than ever to meet the needs of terminally ill patients and their families. (Appropriate Examples) We hope the ranking will spark public discussion because that's certainly needed.
- ***How does our state's relatively low ranking reflect on you and other hospice providers?***
The ranking is a rough yardstick, not a perfect measuring tool and it reflects use of services, not quality. What's important is that the ranking spark public discussion and help all parties: physicians, patients and end of life providers, to strive for the best end of life care possible. Excellent, gold-standard end of life care is within our reach.
- ***Where, why and how are you failing?***
Hospice and palliative care providers are meeting the needs of terminally ill patients and their families in greater numbers more far-reaching ways than ever before. Here at xxx, we are xxx

Need/Value of Report Card

Bridge immediately to the need for public discussion.

Example:

- ***Do you think a report card of sorts was necessary?***
We think it can be very beneficial if it sparks public discussion.

- ***What's the value?***
Sparking public discussion. Americans know very little about end of life care options and have discussed it even less. Unlike some health conditions, we will all experience end of life. We should know our options and discuss our preferences with our physician and family.
- ***How would you suggest consumers use this rating?***
As a starting point for further research and discussion. There is some level of hospice or palliative care in most communities. Talk to individuals in those organizations, the NHPCO or the state hospice association. Hospice and palliative care are doing more to care for the diverse needs of terminally ill patients and their families than ever before, but consumers need to know their options and they need to discuss their wishes with family and physician.

Recommended Actions

Agree with the recommendations in general, then bridge to a single recommendation, "We know what Americans want in end of life care. It's available and funded in hospice care. We must make it our priority for patients, their families and physicians to know about it and understand when and how to use it."

Nursing Home Quality Indicators

Talk about the benefit of hospice for nursing home residents.

Example:

- ***CMS launched its national data base of nursing home quality indicators today. Do you agree with this Last Acts assessment that many nursing home residents are in pain and do you think that should have been one of the indicators in the CMS data base?***
I can't comment on the nursing home quality indicators, but I can tell you that hospice and palliative care play a critical role in the end of life care of nursing home residents. Keep in mind that hospice allows many patients to die at home and for nursing home residents, the nursing home is, indeed, their home. Hospice providers work hand-in-hand with most nursing homes to assure nursing home residents the same end of life options as any other terminally ill patient. And there is no reason for any one to suffer through pain at life's end.