

GRAVE WORDS

TOOLS FOR DISCUSSING END-OF-LIFE CHOICES



by Maren Monson, MD

Discussion Guide

Welcome to the Grave Words Discussion Guide. This Guide is meant to help you, as the facilitator, conduct a 2-hour continuing education program for staff on the topic of conducting end-of-life discussions with patients and their families. Should your time be limited, we suggest that you delete the section "Practice", which allows you to adapt the program to approximately one hour.

YOUR WORDS / YOUR STYLE

We assume that you have had some experience with this topic and encourage you to use your own words and style as you facilitate this discussion. The Guide highlights key topic areas and important resources.

About the Film

Learning to talk with patients about resuscitation and other end-of-life care decisions is a challenge for many physicians and other healthcare providers. It is something still rarely taught in medical schools, yet it has become an increasingly important, perhaps even essential, aspect of good medical practice. Produced by a physician, *Grave Words* takes a unique approach to this topic by blending humor, upbeat music, and insightful interviews to confront head on the issues that arise in such end-of-life discussions. Nationally recognized experts offer their counsel in dealing with these issues and a reenacted "ideal conversation" between a physician and a terminally ill patient provides a model for doctors in carrying out these conversations in their own practices. With its balance of humor and reflection, *Grave Words* is at once entertaining, educational, and thought-provoking.

ISBN (VHS) 1-57295-224-5

ISBN (DVD) 1-57295-865-0

Catalog No. VH-224

25 Minutes, Color

©1996, Maren Monsen

Contact:

Fanlight Productions

4196 Washington Street

Boston, MA 02131

www.fanlight.com

(800) 937-4113

Festival Awards

First Place, International Health and Medical Film Festival

Second Place, Association for Death Education & Counseling

Bronze Apple, National Educational Media Network

Silver Medal, CINDY Competition

Gold Medal, Regional Cinema in Industry Competition

Silver Medal, International Cinema in Industry Competition



GRAVE WORDS

DISCUSSION GUIDE FOR PHYSICIAN TRAINING

TOPIC

DISCUSSION

Pre-Test

Before we get started, please complete this short quiz. We will be discussing these issues as part of our program today (see Appendix A.)

Opening

What comes to mind as you think about having a conversation with a patient or family-member regarding end-of-life decisions? For instance:

- Competency,
- Involving family members,
- A patient may be suspicious about my bringing up the topic.

All of you have had some experiences in speaking with patients and their families about these kinds of issues. Some of us are more comfortable about this topic than others. This session is expected to provide an opportunity for us to learn from each other's experiences and perhaps pick up some tips on how to broach the subject more effectively.

Show **Grave Words...**

TOPIC

DISCUSSION

What the research tells us about conducting end-of-life discussions (see Appendix III for documentation.)

- Most patients want to discuss their values and wishes about end-of-life care with their physicians and they expect their physician to bring up the topic.
- Physicians believe that most patients would have a hard time discussing these sensitive issues.
- Research has found that most patients are never asked about their wishes.
- Some research has found that physicians (and surrogates) are more likely to act on their personal values rather than on the patient's expressed values.

Both patients and provider tend to overestimate the efficacy of resuscitation efforts.

What are the survival to discharge outcomes of resuscitation in different scenarios?

- General in-patient wards 12%
- Metastatic cancer <1%
- Sepsis <1%
- Renal failure 3%

Personal Views

As you think about examples of conversations you have had with patients, why do you think it is so difficult to talk about end-of-life issues?

Medical Terminology

What are some examples of medical jargon that are commonly used? What would be better ways of saying the same thing?

How would you describe resuscitation to a patient in a clear, direct manner without using jargon? (“use of the word attempted resuscitation, etc.”)

TOPIC

DISCUSSION

Getting to the Point:
the Patient's Views

Setting 1: in the office

Initiating the Conversation:

(As a part of routine preventative care):
As a matter of routine, I ask all of my patients whether or not they have an advance directive. Have you ever heard of advance directive?

Having the Conversation:
(Incorporate Cultural Diversity)

(If not, explain): An advance directive is like a living will; I recommend that you complete a durable power of attorney for health care as it allows you to appoint someone to speak for yourself AND it allows you to put in writing your wishes about life support. It's easy to complete – it doesn't require a lawyer and you can pick up a copy in Health Education.) It is important for all adults to have a completed DPAHC on file, just in case of emergency.

Setting 2: at the bedside

Initiating the Conversation:

Mr. Brown/Ms. Brown, do you have a durable power of attorney for health care or have you appointed someone to speak for you in the event that you become so ill that you cannot speak for yourself? IF YES, good, I would like to make sure that we have a copy of that form for our charts. Can you or a family member bring one in? IF NO, since we can't predict the course of your illness, I am concerned that we have some idea about your wishes regarding life support.

If you are unable to speak for yourself, who would you want to speak for you?

TOPIC

DISCUSSION

Having the Conversation

(Document the conversation in the chart. Be sure to write the name of a surrogate if one is mentioned.)

Have you given this some thought- such as if you required help in breathing, or artificial nutrition or water? If your heart stopped, would you want me to attempt to get it beating again? What kind of quality of life is important to you? What scares you the most when you think about ___? Tell me more about what you mean when you say... (discussion ensues). I appreciate how hard this must be to talk about but it is important for me to hear your views.

Important discussion points:

- What phrases were used in the video that you will use in the future? And what would you have said differently? How can you get the patient to clarify his/her wishes?
- When do you think discussions of this type should be brought up? How will you know it's the "right" time?

How would you discuss code status with a patient who you feel should not be resuscitated?

TOPIC

DISCUSSION

Practice

Talking about having this discussion with patients can be different from actually doing it. Everybody has their own style. The more you have a chance to have these kinds of discussions, the easier it becomes to find your own personal style and terminology.

In order to give you a chance to “run through” your personal script, I would like for you to turn to a partner and take a few minutes to try out your questions – how would you bring up the topic and what would you say to prompt your patient to feel like they could speak honestly and comfortably about this topic with you? Take enough time for both of you to have a chance to practice.

Debrief

What was that like? What worked and what didn't? What do you anticipate will be the responses?

Documentation

A documented conversation in the chart between patient and physician is the next best evidence of a patient's wishes when no written advance directive exists. Be sure to describe such a conversation in the chart notes, taking special care to write what decisions were made and why, what values were expressed and who would speak for the patient if the patient were unable to speak for him/herself.

Resources

See Appendices

Closing: Post-Test Evaluation

APPENDIX A

Pre- / Post-Assessment

1. Please indicate whether you believe the following statements are “true” or “false” by circling one of the response categories.

a) Research shows that most people find discussions about life support and end of life planning disturbing or upsetting. True False

b) Family members and patients’ physicians usually make decisions for incompetent patients that reflect the family members’ and providers’ own values as opposed to the patients’ values. True False

c) Approximately 40% of people in the United States have completed an advance directive (such as a Durable Power of Attorney for Health Care.) True False

d) A patient’s verbal statement about his or her life support views is not considered valid unless documented in an advance directive. True False

2. How many times have you participated in end-of-life planning discussions with a patient (e.g. discussion of do-not-resuscitate status, life support wishes, advance directives, appointing a surrogate decision maker.)

Number of Times You Have Discussed
End-of-Life Planning

0-5 6-10 11-20 >20

3. On a scale from 1 to 10, how confident do you feel about initiating and conducting end-of-life planning discussions with patients?

1 2 3 4 5 6 7 8 9 10
Not Confident Very Confident

4. On a scale from 1 to 10, how familiar are you with the resources available to help you, patients, and families to make end-of-life planning decisions?

1 2 3 4 5 6 7 8 9 10
Not Confident Very Confident

APPENDIX B

Pre- / Post-Assessment (with Answers)

1. Please indicate whether you believe the following statements are “true” or “false” by circling one of the response categories.

- | | | |
|---|--------------------------|---|
| a) Research shows that most people find discussions about life support and end of life planning disturbing or upsetting. | True False
X | ♦ Most people want to talk about these issues and expect their provider to bring the topic up. |
| b) Family members and patients’ physicians usually make decisions for incompetent patients that reflect the family members’ and providers’ own values as opposed to the patients’ values. | True False
X | ♦ Research shows providers and family members are more apt to follow their own personal values rather than the patient’s. |
| c) Approximately 40% of people in the United States have completed an advance directive (such as a Durable Power of Attorney for Health Care.) | True False
X | ♦ Surveys indicate that about 10 – 15% of the population has some type of AD. |
| d) A patient’s verbal statement about his or her life support views is not considered valid unless documented in an advance | True False
X | ♦ A verbal statement documented in the medical chart is as valid as a written AD. |

2. How many times have you participated in end-of-life planning discussions with a patient (e.g. discussion of don-not-resuscitate status, life support wishes, advance directives, appointing a surrogate decision maker.)

Number of Times You Have Discussed
End-of-Life Planning

0-5	6-10	11-20	>20
-----	------	-------	-----

3. On a scale from 1 to 10, how confident do you feel about initiating and conducting end-of-life planning discussions with patients?

1	2	3	4	5	6	7	8	9	10
Not Confident					Very Confident				

4. On a scale from 1 to 10, how familiar are you with the resources available to help you, patients, and families to make end-of-life planning decisions?

1	2	3	4	5	6	7	8	9	10
Not Confident					Very Confident				

APPENDIX C

Studies have shown that patients experience an increased sense of trust and well-being when they have had a discussion with their physician about their expectations and wishes for treatment at the end of life.¹ Some studies have shown cost savings associated with the use of advance directives², which are often associated with such discussions; other studies have not confirmed this.³ Regardless of any cost savings, if a patients' views are known prior to a medical crisis it is more likely that the treatment measures and technologies used will be appropriately directed toward the patient's goals and wishes.⁴ For example, if a patient desires no heroic measures be taken at the end of life, unwanted intensive care unit interventions may be avoided, and more timely hospice or home health care can be initiated.

Patients generally desire a conversation with their physician about advance directives and their end-of-life care views, but expect the physician to initiate such a discussion.⁵ Most physicians do not report having these discussions with the majority of their frail patients.⁶ Studies have shown no adverse affects on patients from having these discussions with physicians.⁷ There are some inherent problems with advance directives, i.e. patients may not accurately complete the legal document,⁸ physicians may be more prone to follow their personal values rather than the patient's values,⁹ surrogates are more likely to select life support measures which reflect their personal values rather than their loved one's,¹⁰ and patients may not fully understand the preferences they have indicated on their forms.¹¹ However, even with these constraints, patients who have documented their preferences for life support and who have legally appointed surrogates increase their chances that providers can respect their wishes in a time of crisis as compared to patients whose values we know nothing about.¹²

REFERENCES:

- ¹ Virmani J, Schneiderman LJ, Kaplan RM, Relationship of advance directives to physician-patient communication. *Arch Intern Med.* 1994;154:909-913. Smucker WD, et al, Elderly outpatient respond favorably to a physician-initiated advance directive discussion. *J Am Board Fam Pract.* 1993;6:473-482. Lo B, McLeod GA, Saika G, patient attitudes to discussing life-sustaining treatment. *Arch Intern Med.* 1986;146:1613-1615.
- ² Chambers CV, et al, Relationship of advance directives to hospital charges in a medicare Population. *Arch Intern med.* 1994;154:541-547. Weeks WB, et al, Advance directives and the cost of terminal hospitalization. *Arch Intern Med.* 1994;154:2077-2083.
- ³ Schneiderman LJ, et al, Effect of offering advance directives on medical treatments and costs. *Ann Intern Med.* 1992;117:5599-5606. Teno JM, et al, Do formal advance directives affect resuscitation decisions and the use of resources for seriously ill patients? *J Clin Ethics,* 1994;5:23-30.
- ⁴ Swartz RD, Perry E, Advance directives are associated with "good deaths" in chronic dialysis patients. *J Am Soc Nephrol.,* 1993;3:1623-1630. See also articles in footnote 3.
- ⁵ Emanuel LL, et al, Advance directives for medical care; a case for greater use. *N Engl J Med.* 1991;324:889-895.
- ⁶ Morrison RS, Morrison EW, Glickman DF, physician reluctance to discuss advance directives. *Arch Intern Med,* 1994;154:2311-2318. Solomon, et al, Decisions near the end of life: professional views on life-sustaining treatments. *Am J Public Health.,* 1993;83:14-23. Brunetti, Carperos, and Westlund, Patient's attitudes towards living wills and cardiopulmonary resuscitation, *J Gen Intern Med.* 1991; 6:323-329.

continued...

REFERENCES *Continued:*

⁷ Kellogg, Crain, Corwin, and Brickner, Life-Sustaining interventions in frail elderly persons – talking about choices. *Arch Intern Med*;1992;152:2317-2320.

⁸ Rubin, Susan M, Strull WM, Fialkow MF, Weiss SJ and Lo B, Increasing the Completion of the Durable Power of Attorney for Health Care, *JAMA*, 1994: 271: 209.

⁹ Schneiderman LJ, Kaplan RM, Peralman RA and Teetzel H, *The Journal of clinical Ethics*: 1993:4: 28; The SUPPORT Principal Investigators, *The Journal of the American Medical Association*: 1995:274:20: 1591 – 1598.

¹⁰ Layde, Peter M. et al. Surrogates' predictions of seriously ill patients' resuscitation preferences. *Archives of Family Medicine*, vol 4, June, 1995. *Archives of Internal Medicine*, Jan 10, 1994.

¹¹ Jacobson JA, White BE, Battin, MP, Francis LP, Green DJ and Kasworm ES. Patients' Understanding and Use of Advance Directives, *Western Journal of Medicine* 1994: 160:232-236.

¹² Gillick, Muriel R. A Broader Role for Advance Medical Planning, *Annals of Internal Medicine*: 1995: 123: 621-624.