

COMMUNICATING WITH PATIENTS AND FAMILIES ABOUT THE END OF LIFE

OBJECTIVES

The ability to communicate well is essential to the practice of palliative care, in which the team must frequently discuss sensitive topics with patients and their families. Because patients are free to accept or refuse treatments, it is essential to communicate prognosis, to clarify the patient's goals of care, and to help the patient consider how different treatment options may or may not align with those goals. Patient-family-caregiver group dynamics play an important role in decision making, both informally and within the structured setting of a formal family meeting. Outstanding communication is a skill that can be developed through practice. The sections below will provide guidance in how to broach difficult topics in different clinical settings. You will participate in a number of other family meetings in this course, and the team will debrief after each meeting. This practice allows team members at every level to continue to improve their communication skills.

TOPICS

- Overview of the family meeting
- Setting the scene: SPIKES/NURSE
- Goal-setting: PERSON
- Discussing DNR orders
- Useful phrases

The Family Meeting: End Of Life Goal Setting And Future Planning

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Fast Fact #227: <https://www.capc.org/fast-facts/227-family-meeting-end-life-goal-setting-and-future-planning/>

Background: End-of-life goal setting is a key palliative care skill, typically occurring as part of a family meeting (see Fast Fact #16, Fast Fact #65, Fast Fact #222 - Fast Fact #226). This Fast Fact discusses an approach to goal setting when the expected length of life is short.

Establishing patient-centered goals

Here is an example of how to start the conversation (the patient should be given sufficient time to respond to each of these questions):

I/we have discussed your current condition and that time may be short. With that in mind –

- 1 *What are you hoping for now?*
- 2 *What is important to you?*
- 3 *What do you need to accomplish?*
- 4 *Who do you need to see in the time that is left?*

Common responses invoke family, home, and comfort; often surviving until a specific future family event/date or visit with a key family member is described as an important goal. Re-state your understanding: *What I hear you saying is that you want to be home, comfortable, and survive until your daughter gives birth – you hope to meet your next grandchild.* Note: if you believe the patient's goal of survival to a specific event/date is not practical, it is important to say so and discuss alternative plans.

Recommend a care plan based on the goals

Once the goal(s) is/are established, you can then review the patient's current treatments (e.g. antibiotics, chemotherapy), monitoring (e.g. pulse oximetry), planned tests (e.g. colonoscopy), and medications (e.g. anti-hypertensives), and decide which will help meet, or not, the patient's goals. Anything that will not help meet the goals should be discussed for potential discontinuation. Depending on the specific disease/patient condition, other issues that are naturally discussed at this point include:

- Future hospitalizations, ICU admissions, laboratory and radiology tests.
- Resuscitation orders/code status (see Fast Fact #23 and Fast Fact #24).
- Current/future use of blood products, antibiotics, artificial hydration/nutrition.
- If present, the potential continuation or stopping of dialysis or cardiac devices.
- Role of a second (or third) opinion.
- Exploration of experimental therapy.
- Exploration of treatment options the patient or family may bring into the conversation.
- Disposition options to best meet the goals (e.g. home hospice referral).

Note: There is no need to ask about each option as a yes/no question (*Do you want blood products?*). Based on what you know about the patient's goals, make a recommendation about what should and should not be done in light of the patient's goals, condition and prognosis. If you are unsure, you can explore the issue with the patient/family (*Given that your dad wanted to get home as soon as possible and yet he was also willing to do easy things that might help him live longer, I am unsure whether it makes sense to stay in the hospital an extra day or two to finish the antibiotics. What do you think he would say?*).

'Long-shot' goals

If patients are going to pursue 'long-shot' or experimental therapy, perhaps even against the recommendation of the treating team, it is useful to ensure the following:

- Reinforce the team's respect for the decision, and desire to make sure the treatment has the best possible chance of working.
- Simultaneously try to maximize quality of life in the present, including the best possible pain and symptom management and support.
- Encourage the patient and family to prepare in case treatment is not successful and the patient dies sooner rather than later. Useful language is to say, *I'd encourage us all to hope for the best, but prepare for the worst.*
- Reinforce that the team will not abandon the patient and family even if the decision is not what is being recommended.

Close the meeting

Following this discussion, restate your understanding of the patient's goals and agreed-upon next steps to meet those goals, invite and answer questions, and close the meeting.

Discussion & documentation

Discuss the goals with key staff not in attendance (e.g. consulting physicians, patient's nurse, discharge planner, primary care provider). Document the goals, preferably using a templated family meeting note (see Reference 1): who was present, what was discussed (e.g. treatment options, prognosis), what was decided, next steps.

Debriefing

A useful step after every family meeting is to debrief the process – what went well, what could have been improved and, most importantly, addressing the emotional reaction and needs of the care team.

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SPIKES: A Framework for Breaking Bad News to Patients With Cancer

Marcelle Kaplan, RN, MS, AOCN®, CBCN®

SPIKES is an acronym for presenting distressing information in an organized manner to patients and families. The SPIKES protocol provides a step-wise framework for difficult discussions such as when cancer recurs or when palliative or hospice care is indicated. Each letter represents a phase in the six-step sequence. S stands for setting, P for perception, I for invitation or information, K for knowledge, E for empathy, and S for summarize or strategize. Breaking bad news is a complex communication task, but following the SPIKES protocol can help ease the distress felt by the patient who is receiving the news and the healthcare professional who is breaking the news. Key components of the SPIKES strategy include demonstrating empathy, acknowledging and validating the patient's feelings, exploring the patient's understanding and acceptance of the bad news, and providing information about possible interventions. Having a plan of action provides structure for this difficult discussion and helps support all involved.

M.J. is a 68-year-old woman who has been disease free since being treated for stage IIA breast cancer 15 years ago with a right-side modified radical mastectomy and adjuvant chemotherapy, followed by five years of tamoxifen therapy. She has two adult children, four grandchildren, and is newly retired from her job as a school secretary. She and her husband have been making plans to take a month-long cruise. However, M.J. recently had a persistent cough that developed into pneumonia. A chest x-ray revealed several lesions in her right lung. Today she is returning with her husband to the oncology clinic to learn the results of a full-body positron-emission test (PET) and computed tomography (CT) scan.

The medical oncologist and the oncology nurse are aware that the PET/CT scan has revealed areas of increased activity in M.J.'s right lung and liver that most likely represent metastatic breast cancer. They know that this portends a poor prognosis and that M.J. needs immediate definitive tissue diagnosis and treatment. M.J. had been anxious for several years about the possibility of disease recurrence but, in recent years, she thought she "had beat it." The immediate problem for the oncology team is how to break the bad news to M.J. in the most gentle and therapeutic way.

The Intervention: Breaking Bad News

This type of discussion usually is quite difficult and uncomfortable for healthcare professionals to participate in. Often they have little preparation and experience in how to support the patient in a constructive, empathetic manner when delivering bad news. Having a prepared plan of action can help support all the participants in this difficult discussion.

The oncology team has four goals in breaking the news to M.J.: (a) learn what she already knows about the situation and determine her readiness to hear the news, (b) provide clear information tailored to her needs and desire to know, (c) provide empathy and emotional support, and (d) develop a treatment plan that takes her wishes into account (Baile et al., 2000).

A useful strategy for accomplishing these goals employs a six-step protocol for breaking bad news, known as SPIKES. SPIKES is an acronym for presenting distressing information in an organized manner to patients and families. It pro-

vides a step-wise structure for difficult discussions, such as when cancer recurs, or when treatment options have been exhausted and palliative or hospice care is indicated. Each letter represents a phase in the six-step framework (Back, Arnold, Baile, Tulsky, & Fryer-Edwards, 2005; Baile et al., 2000; Buckman, 2005; Finlay & Casarett, 2009) (see Figure 1).

The SPIKES Protocol

S = Setting

Respect and empathy for the patient is shown by choosing a setting which provides quiet and privacy. Pagers are turned to vibrate and calls are held. Significant others are included in the discussion as the patient wishes. The person delivering the bad news demonstrates good listening skills and focuses his or her attention on the patient in a calm, engaged manner.

P = Perception

Before launching into a description of the plan of care with the patient and

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S = Setting
P = Perception
I = Invitation or information
K = Knowledge
E = Empathy
S = Summarize or strategize

Figure 1. SPIKES: A Structured Plan for Delivering Bad News

family members, it is important to understand how much they know and what their perceptions are about the medical situation. The extent of their knowledge and their feelings can be assessed using open-ended questions, such as, “What have you been told so far?” “Do you know why the PET/CT was ordered?” “Are you worried that this might be something serious?”

I = Invitation or Information

This is the step in which patients and family members are asked directly about how much and what kind of information will be helpful to them. Their preferred learning styles and need for information are solicited and taken into account during this difficult discussion. Simple questions about how much information they want and how the information will be used can help guide the oncology team in advancing to the next step in the framework

K = Knowledge

This is the phase in which the bad news is shared with the patient and family members. It should be introduced gently. A statement such as “I have some serious news to tell you” or “I have some bad news to share with you” lets the patient prepare psychologically. Information about the extent of disease and plan of care is provided directly and honestly in small segments. The patient and family members are frequently asked whether they understand what they are being told and whether they need additional clarification. Clear, nonmedical language that matches the patient’s education level is used; jargon and technical terms are avoided. After the bad news is shared, time is allowed to let the patient absorb the information and respond.

E = Empathy

The key to an empathetic response lies in acknowledging the emotions and

reactions of the patient and family during this painful discussion and responding to them in an appropriate manner. Statements such as “I wish the news was better” or “This is obviously distressing news” convey empathy.

S = Summarize or Strategize

The final step in the SPIKES discussion is to summarize the information that has been presented in language that the patient can easily understand and to present a strategic plan for further interven-

Naming

Naming an emotion is a way of showing sensitivity to the patient’s distress. Open-ended questions, such as “I wonder if you’re feeling angry?” are preferred over statements such as “You must be angry.”

Understanding

Having a clear understanding of the patient’s fears and concerns allows the healthcare professional to make truly empathetic responses. Premature reassurances are avoided until the patient’s feelings and emotions are validated.

Respecting

Treating the patient with respect and dignity is essential to establishing an empathetic, reciprocal relationship. Messages that permit, acknowledge, and respect a patient’s expression of emotion can be sent both non-verbally, through body language and touch, and verbally, with statements that match the patient’s level of distress.

Supporting

Statements that show support for the patient’s ability to cope, that share information about available resources, and that provide reassurance about not being abandoned can help allay patient fears and reinforce their coping skills.

Exploring

Asking direct focused questions and asking for clarification of earlier responses gives patients the permission and opportunity to share their inner emotions and concerns. Checking frequently with the patient about additional questions or concerns helps draw out other issues and emotions that the patient may have been hesitant to reveal.

Figure 2. NURSE: A Method for Responding to Patients’ Emotions With Empathy

Note. Based on information from Back et al., 2005.

tion. Questions aimed at verifying that the patient understands the proposed plan and is able to make the decision to participate can include “Does this make sense to you?” “Are you clear about the next steps?” and “Do you have enough information to make a decision?”

Another helpful acronym for responding to and accepting patients’ emotional distress is called NURSE (Back et al., 2005) and is described in Figure 2.

The SPIKES Discussion Outcome

The meeting with M.J. and her husband took place in a quiet office away from the infusion unit. Both appeared anxious and apprehensive. M.J. stated that she had been dreading this meeting because they were sure the news would be bad. They knew the PET/CT test had been ordered to evaluate the extent of disease and were apprehensive about the results. The oncology team spent 40 minutes delivering the bad news using the steps in the SPIKES framework. They focused their full attention on M.J. and her husband throughout the discussion with no perceived sense of rush. At the end of the meeting, M.J. stated that it was a shock to actually hear the bad news and it would take a while for her to absorb it. Both she and her husband reported that they understood the information presented to them and the recommendations for additional diagnostic procedures and plan of treatment. They planned to have a discussion with their children before making a decision on how to proceed and would get back to the team after the weekend.

Conclusion

Breaking bad news is a complex communication task, but following the step-wise sequence of the SPIKES protocol can help ease the distress felt by both parties: the patient, who is receiving the news, and the healthcare professional, who is breaking the news. Key components of the SPIKES strategy include demonstrating empathy, acknowledging and validating the patient’s feelings, exploring the patient’s understanding and acceptance of the bad news, and providing information about possible interventions. Having a plan of action provides structure for

this difficult discussion and helps support all involved.

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Do You Have an Interesting Topic to Share?

Supportive Care provides readers with information on symptom management and palliative care issues. Length should be no more than 1,000–1,500 words, exclusive of tables, figures, insets, and references. If interested, contact Associate Editor Marcelle Kaplan, RN, MS, AOCN®, CBCN®, at marcelle.kaplan@gmail.com.

Establishing Goals of Care at Any Stage of Illness: The PERSON Mnemonic

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Dear Editor:

As a palliative care team members at large, academic hospitals, we are often called to discuss a patient's "goals of care," which we approach in a standardized fashion. Interestingly, despite the fact that "goals of care" is oft mentioned in the literature,^{1–4} there are very few guidelines on how to approach such a conversation.¹

We feel compelled to find a structure for goals of care conversations for several reasons: Given the task-oriented nature of medicine and the fact that our team frequently interacts with multidisciplinary learners, we find that we need a way to clarify that goals of care is not just code status and is different from the plan of care. Two, we have not found the SPIKES model⁵ to be helpful in early goals of care conversations⁶ given that it is specifically focused on sharing news. And three, recommendations for patient-centered goals of care communication go back as far as 1996⁷ and yet there is no consensus approach to having these conversations.

To these ends, our team has developed the following approach to having goals of care conversations at any stage of serious illness. It begins like all other important conversations, with consideration for the setting, which should be as personal and quiet as possible. Ideally, all interested parties should be together and in person. Following this, we encourage ourselves and our learners to remember to know the PERSON prior to making important medical decisions.

- Perception: understand the patient and family perception of current health status using open-ended questions and avoiding assumptions (e.g., "What have the doctors told you?")
- Explore the patient's life prior to present illness using inquiring and reflection statements and aligning with the patient by acknowledging sources of hope (e.g., "What was your life like before you got sick?")
- Relate the patient's story to medical reality and tie medical information to the patient's world (e.g., "It sounds like before you got sick you liked to...but it's been a long time since you've been able to do that.")
- Sources of worry: explore the patient's fears using future-oriented statements while sharing your own fears using hope/worry statements (e.g., "What's important to you now that you know your life will be shorter than you'd hoped?")

- Outline the plan for going forward using simple, declarative sentences including any time-limited trials
- Notify those who need to know including other family, multidisciplinary team members, and treating teams

We believe this model for goals of care conversations adds to practice in that it is applicable across the spectrum of illness and that it functions as both an inquiry and an advocacy tool. Next steps for the evolution of this tool include hearing from readers of this journal with their thoughts and suggestions. Additionally, we will be studying the PERSON model's effectiveness at improving medical student, resident, and fellow understanding of and comfort with goals of care conversations.

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Discussing DNR Orders – Part 1

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Fast Fact #23: <https://www.capc.org/fast-facts/23-discussing-dnr-orders-part-1/>

Background: ‘Code status’ discussions with seriously ill patients should always take place in the context of the larger goals of care, using a step-wise approach. This Fast Fact introduces an approach to having these discussions; Fast Fact #24 discusses disagreements about ‘code status.’ Prior to any discussion of a do-not-resuscitate (DNR) order, physicians must know the data defining outcomes and morbidity of cardiopulmonary resuscitation in different patient populations (see Fast Fact #179).

1. Establish the setting.

Ensure comfort and privacy; sit down next to the patient. Ask if family members or others should be present. Introduce the subject with a phrase such as: I’d like to talk with you about possible health care decisions in the future.

2. What does the patient understand?

An informed decision about DNR status is only possible if the patient has a clear understanding of their illness and prognosis. Ask an open-ended question to elicit patient understanding about their current health situation. It is important to get the patient talking – if the doctor is doing all the talking, it is unlikely that the rest of the conversation will go well. Consider starting with phrases such as: What do you understand about your current health situation? What have the doctors told you about your condition? If the patient does not know/appreciate their current status this is time to review that information.

3. What does the patient expect?

Ask the patient to consider the future. Examples of ways to start this discussion are What do you expect in the future? or What goals do you have for the time you have left—what is important to you? This step allows you to listen while the patient describes a real or imagined future. Many patients with advanced disease use this opening to voice their thoughts about dying—typically mentioning comfort, family, and home, as their goals of care. If there is a sharp discontinuity between what you expect and what the patient expects, this is the time to clarify.

Listen carefully to the patient’s responses; most patients have thought a lot about dying, and only need permission to talk about what they have been thinking. Setting up the conversation in this way permits the physician to respond with clarifying and confirming comments such as:

So what you’re saying is – you want to be as comfortable as possible when the time comes? Or – What you’ve said is – you want us to do everything we can to fight, but when the time comes, you want to die peacefully? Whenever possible, ask patients to explain the values that underlie their decisions: Can you explain why you feel that way?

4. Discuss a DNR order.

Use language that the patient will understand; give information in small pieces. Don’t introduce CPR in mechanistic terms (e.g. “starting the heart” or “putting on a breathing machine”). Never say Do you want us to do everything? “Everything” is euphemistic and easily misinterpreted. Using the word “die” helps to clarify that CPR is a treatment that tries to reverse death. To most lay-people, when the heart and/or lungs stop, the patient dies.

If the patient and doctor mutually recognize that death is approaching and the goals of care are comfort, then CPR is not an appropriate medical intervention and a clear recommendation against CPR should be made. You can say: *We have agreed that the goals of care are to keep you comfortable and get you home. With this in mind, I do not recommend the use of artificial or heroic means to keep you alive. If you agree with this, I will write an order in the chart that if you die, no attempt to resuscitate you will be made.*

If the clinical situation is more ambiguous in terms of prognosis and goals of care, and you have no clear recommendation, the issue of DNR can be raised by asking: If you should die in spite of all of our efforts, do you want us to use heroic measures to attempt to bring you back? Or, How do you want things to be when you die? If you are asked to explain “heroic measures”, then describe the purpose, risks and benefits of CPR in greater detail. The clinical pearl here is to start general and become specific later in the conversation.

5. Respond to emotions.

Strong emotions are common when discussing death. Typically the emotional response is brief. The most profound initial response a physician can make may be silence, providing a reassuring touch, and offering facial tissues (see Fast Fact #29).

6. Establish a plan.

Clarify the orders and plans that will accomplish the overall goals you have discussed, not just the DNR order. A DNR order does not address any aspect of care other than preventing the use of CPR. It is unwise and poor practice to use DNR status as a proxy for other life-sustaining therapies. Consider using words: We will continue maximal medical therapy to meet your goals. However, if you die, we won't use CPR to bring you back. Or, It sounds like we should move to a plan that maximizes your comfort. Therefore, in addition to a DNR order, I'd like to talk further with you how we can best do that.

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Discussing DNR Orders – Part 2

Charles F von Gunten MD, David E Weissman MD

Fast Fact #24: <https://www.capc.org/fast-facts/24-discussing-dnr-orders-part-2/>

Introduction: The basic steps in the DNR discussion for seriously ill hospitalized patients were described in Fast Fact #23. If you have followed those steps, what do you do if the patient or family/surrogate continues to want CPR and you think it is not in the patient's best interest? The seemingly unreasonable request for CPR typically stems from one of several themes:

1. Inaccurate information about CPR.

The general public has an inflated perception of CPR success. While most people believe that CPR works 60-85% of the time, in fact the actual survival to hospital discharge is more like 10-15% for all patients, and less than 5% for the elderly and those with serious illnesses. This is a time to review/clarify the indications, contraindications, potential outcomes and morbidity of CPR. Start the discussion by asking, "What do you know about CPR?"

2. Hopes, fears, and guilt.

Be aware that guilt (I haven't lived nearby to care for my dying mother) and fear (I am afraid to make a decision that could lead to my wife's death) are common motivating emotions for a persistent CPR request. Some patients or families need to be given an explicit recommendation, or permission from the physician, to stop all efforts to prolong life, to be told that that death is coming and that they no longer have to continue "fighting". Whenever possible, try to identify the underlying emotions and offer empathic comments that open the door to further conversation. This decision seems very hard for you. I want to give you the best medical care possible; I know you still want CPR, can you tell me more about your decision?

Agreeing to a DNR order for many patients feels equivalent to them "choosing" to die. Acceptance of impending death occurs over a vastly different time course for different patients/families; for some, it never occurs. Some patients see CPR as a "last chance" for continued life. Probe with open-ended questions: What do you expect to happen? What do you think would be done differently, after the resuscitation, that wasn't being done before? Many patients describe hope for a new treatment. Use the opportunity to respond by describing that you are doing everything in your power to prolong their life before a cardiopulmonary arrest – you wouldn't be "saving something" to do after they had died. If patients are not ready for a DNR order, don't let it distract you from other important end-of-life care needs;

emphasize the goals that you are trying to achieve; save a repeat discussion for a future time; good care, relationship building and time will help resolve most conflicts.

3. Distrust of the medical care system.

Patients or families may give you a clue that there is a fundamental distrust of doctors or the medical system; this should be addressed openly. What you said makes me wonder if you may not have full trust in the doctors and nurses to do what is best for you? Can you tell me about your concerns?

4. Managing persistent requests for CPR.

Decide if you believe that CPR represents a futile medical treatment—that is, CPR cannot be expected to either restore cardiopulmonary function or to achieve the expressed goals of the patient (see Fast Fact #136). Physicians are not legally or ethically obligated to participate in a futile medical treatment, and some facilities have a policy that a physician may enter a DNR order in the chart against patient wishes. Aside from writing a DNR order without patient or family agreement, other options at this time include:

Transfer care to another physician chosen by the patient/family.

Plan to perform CPR at the time of death – but don't end the discussion. Engage the patient about her or his wishes if she or he survive the resuscitation attempt. Tell the patient that you need guidance because it is very likely that if she or he survives CPR, they will be on life support in the ICU, and they may not be able to make decisions for themselves; ask them (or the family) to help you determine guidelines for deciding whether to continue life-support measures. If not already done, clarify if there is a legal surrogate decision-maker.

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COMMUNICATION PHRASES IN PALLIATIVE CARE

Advance Care Planning

- I'd like to talk with you about possible health care decisions in the future. This is something I do with all my patients so I can be sure that I know and can follow your wishes. Have you ever completed an Advance Directive?
- *What do you understand about your health situation?*
- *If you were unable to make your own medical decisions, who would like to make them for you? Have you spoken to this person?*
- *When you think about dying, have you thought about what the end would be like or how you would like it to be?*
- *Have you discussed your wishes with your family?*

Determining Decision Making Capacity

- *Will you describe your current condition? What the doctors have told you?*
- *Tell me the options for treating "X" that we have just discussed.*
- *Explain to me why you feel that way?*

Breaking Bad News

- *What do you understand about your condition?*
- *I'm afraid I have some bad news. I wish things were different, but the test results are not good; The (test name) showed X.*
- Address emotional reaction (see back page)
- *I want to be sure you understand what we have talked about; can you summarize for me what we have discussed?*
- *Write down any questions that come to mind, let's to plan to meet again (time/date).*

Quality of Life –phrases that will help you understand the illness's impact

- *How has your disease interfered with your daily activities; your family and friends?*
- *Have you been feeling worried or sad about your illness?*
- *What symptoms bother you the most? What concerns you the most?*
- *How have your religious beliefs been affected by your illness?*
- *Many patients wonder about the meaning of all this—do you?*

Prognosis

- *Tell me how you spend your day; how much time do you spend laying down or resting—is it more or less than 50% of the time; has this changed recently?*
- *Has anyone talked to you about what to expect?*
- *Do you have any a sense of how much time is left? s this something you would like to talk about?*
- *Although I can't give you an exact time, in general, patients with your condition live ___ wks/months to ___ wks/months.*
- *Based on what you have told me, and what I see, I believe you are dying.*

Goal Setting

- *Knowing that time is short, what goals do you have for the time you have left—what is important to you? What do you need to do?*
- *What are your goals for this last phase of your life?*

Talking with Surrogate Decision Makers

- *These decisions are very hard; if (patients name) were sitting with us today, what do you think he/she would say?*
- *Can you tell me why you feel that way?*
- *How will the decision affect you and other family members.*
- *I believe that (patients name) is dying.*

Discussing Artificial Feeding/Hydration

- *What do you know about artificial ways to provide food?*
- *All dying patients lose their interest in eating in the days to weeks leading up to death, this is the body's signal that death is coming.*
- *I am recommending that the (tube feedings, hydration, etc.) be discontinued (or not started) as these will not improve his/her living; these treatments, if used, may only prolong his/her dying.*
- *Your (relation) will not suffer; we will do everything necessary to ensure comfort.*
- *Your (relation) is dying from (disease); he/she is not dying from dehydration or starvation.*

Cross-Cultural – Understanding others views of illness

- *I know different people have very different ways of understanding illness...Please help me understand how you see things.*
- *What do you call the problem, Tell me what you think the illness does, What do you think the natural course of the illness is, What do you fear?*
- *Who do you turn to for help, Who should be involved in decision making?*

- *How do you think the sickness should be treated. How do want us to help you?*
- *Some people like to know everything about their disease and be involved in all decision making. Others do not want all the news and would rather the doctor talk to XX? Which kind of person are you? How involved do you want to be in these decisions?*

Discussing Palliative Care or Hospice Referral

- *To meet the goals we've discussed (summarize goals) I've asked the Palliative Care Team to visit with you; they are experts in treating the symptoms you are experiencing. They can help your family deal with the changes brought on by your illness.*
- *You've told me you want to be as independent and comfortable as possible. Hospice care is the best way I know to help you achieve those goals. Hospice is a program that helps the patient and family achieve the goals you've just describe, it's a team of people that help meet the patient's and family's physical, psychological, social and spiritual needs.*

Death Pronouncement

- *I wish there is more we could have done; I'm very sorry for your loss. This must be very difficult for you; is there anyone I can call for you?*
- *In the days to weeks to come, please contact me if I can answer any questions about your (insert relation) illness.*

RESPONDING TO EMOTION

1. Reflect thoughts, emotions or behavior:

- *It seems like you are having a hard time deciding between ____ and ____...*
- *You have been feeling _____...*
- *I see that you are crying...*
- *You seem very ...*

2. Affirmation & respect..

- *Thank you for describing your feelings and thoughts.*
- *I can do a better job as your doctor when I know how you are feeling.*
- *Please tell me more about the sadness you are feeling.*

3. Summarize/paraphrase.

- *We have been talking for awhile about how things are going for you. Let me see if I can summarize what you have said, then you can let me know if I'm on track ...*

4. Make a plan.

- *How can I help? or, What, if anything, would make a difference for you?*
- *I would like to check in with you next week and see how things are going. In the mean time, please let me know if you need to talk before then.*

5. Dealing with Anger

- *It sounds/appears that you are angry?*
- *You appear angry, can you tell me what is upsetting you?*
- *So, you are telling me that you are angry about ____, is that correct?*
- *I wish things were different, how can we move forward? How can I help?*

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