

# Communication and End of Life Decision Making

A Resource Guide for Health Care  
Practitioners



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**“But if you miss being understood by laymen, and fail to put your hearers in this condition, you will miss reality.”**

**-Hippocrates**

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## Introduction

End of life decision making is an ongoing and dynamic process between the patient, family, and health care practitioner. It is decision-making that considers a constellation of physiological, psychosocial, and spiritual concerns and their combined effect on the patient's medical treatment and quality of life at the end of life. This process includes the conversation in which the health care practitioner gives the patient or their loved one bad news, and subsequent conversations related to treatment and care.

Bad news can be defined as any information viewed by a patient as negative to their current and future situation, which results in a cognitive or emotional deficit for a period of time after it is received (Fallowfield and Jenkins, 2004). It is perhaps the most difficult task that a health care practitioner encounters and is often relayed to the patient, under less than desirable circumstances. Given the nature of this complex task and the emotionally charged condition in which the conversation usually takes place, it is critical that health care practitioners are comfortable and competent in their delivery of bad news as it not only often serves as the introduction to the relationship with the patient/family but also as the foundation for future conversations related to decisions about end of life.

End of life communication and decision making is unique. Both health care practitioners and patients enter an emotionally laden situation where they must confront and deal with issues about treatment, care, and the process of dying. There are often many uncertainties about life expectancy as well as treatment outcomes, and high-level communication skills are critical to each end of life decision making discussion. Maguire (1999) found the two most important factors for patients when discussing bad news to be: the patient's perception that the practitioner had provided adequate information, and; the

practitioner's ability to elicit and resolve the patient's concerns prompted by the bad news. Both factors have cognitive, affective and psychosocial characteristics, and without adequate skills, both are difficult to accomplish in an effective manner.

End of life communication is complicated and cannot be taken for granted. It is much more than the giving of and asking for factual information. It joins science to the art of medicine, where the technological medical advances of the past 30 years become secondary and the patient as an individual becomes the focus. While cure is not always achievable, healing, in the form of emotional and spiritual well-being, is always possible. Patient centered communication using collaboration and shared decision making are at the heart of healing for everyone involved.

### **Barriers to Patient/Practitioner Communication**

A number of health care practitioner experts have indicated that the most difficult task in addressing patients' disease processes and prognoses is addressing both the healthcare practitioners and the patient's emotional concerns. Many health care practitioners have difficulty with their own emotions, frequently experience a sense of failure when their effort to cure or save patients is unsuccessful, and have not been taught how to address the psychosocial issues of their patients (Fallowfield & Jenkins, 2004). As a result, they often use a self-protective approach to circumvent their patients' affective concerns by adopting strategies that will prevent deeper conversations. These strategies are further exacerbated when health care practitioners feel that they lack support from their institution or colleagues (Fallowfield & Jenkins, 2004; Macguire, 1999). Behaviors that health care practitioners engage in to avoid patients perceptions of what is happening and their emotional reactions are shown in Table One. Other health care practitioner barriers include time constraints and

the belief that communication skills are not particularly important to the practice of medicine (Hallenbeck, Katz, and Stratos,2003).

**Table 1: Health Care Practitioner Barriers**

Blocking	Lecturing	Collusion	Premature Reassurance
Switching the topic upon receipt of a patient's question that has the potential to evoke an emotional response	Only attending to the physical aspects of patient	Health care practitioner belief that it is better to keep conversation in "safe waters" to prevent upset all the way around	Offering patient advice and reassurance before the main problems have been identified
"Jollyng" patients along to avoid difficult questions	Prevents patient from responding to information provided	Health care practitioner belief that the conversation will take too much time and would harm patients	Explaining away patient's distress as normal
Health care practitioner fear of releasing strong emotions in patients, such as anger or despair that would not be controllable		Health care practitioner belief that patient is fragile and susceptible to harm	

(Adapted from Back, Arnold, Baile, Tulsky and Kelly; 2005; Maquire, 1998)

Similarly, many patients experience barriers to effective communication around end of life communication. When patients receive bad news, they often cannot immediately comprehend what they have been told as they are flooded with emotion. Their flight/fight response comes to the fore in their reaction to the news and their emotions range from anger to denial. For a variety of reasons, some patients may not have the capacity to discuss their concerns. Other patients, taking their cues from their health care practitioners, use various strategies to avoid disclosing their concerns. Table Two outlines some of the behaviors patients engage in to prevent disclosure of their concerns as well as those capacities that may prevent a patient from sharing her/his concerns.

**Table 2: Patient Barriers**

Reaction to Health care practitioner	Fear/Denial	Health care practitioner's Perception	Capacity
Patient belief s/he will burden health care practitioner	Patient belief nothing can be done	Patient belief that s/he will seem ungrateful to health care practitioner	Patient knowledge deficits
Patient belief that health care practitioner is too busy to listen	Patient belief that what is wrong will be confirmed	Patient belief that s/he will seem pathetic to health care practitioner	Patient language deficits
		Patient belief that her/his concerns will be seen as not legitimate	Patient cognitive deficits

(Adapted from Hallenbeck, Katz, and Stratos, 2003; Maguire 1998)

### **Health Care Practitioner Style and Patient Perception**

Similar to the barriers described above, Friedrichsen, Strang, and Carlson (2000) conducted a phenomenological qualitative study related to the patient's perception of health care practitioner communication and behavior in the delivery of bad news. From their study they categorized health care practitioner communication and behavior into six styles and four types of patient/health care practitioner relationships.

Patients described their relationships with health care practitioners as particularly important when receiving life-changing information. The two patient/health care practitioner relationships categorized as personal between well-acquainted persons, and personal between unacquainted persons were described as relationships built on mutual understanding and respect. Patients were comfortable with, felt respected by, and had confidence in these health care practitioners. The two patient/health care practitioner relationships categorized as impersonal between well-acquainted persons, and impersonal between unacquainted persons can be best described as alienating to patients. Patients in these relationships lost confidence in and felt disrespected by these health care practitioners.

A health care practitioner's style and the characteristics of the style play a significant role in the perception of the patient's view of her/his relationship with the

health care practitioner Table Three outlines health care practitioner style, communication characteristics, and the patient’s perception of the relationship.

**Table 3: Style, Characteristics & Perception**

<b>Health care</b>	<b>Style Characteristics</b>	<b>Patient Perception</b>
<b>Inexperienced messenger</b>	Message delivered quickly with no warning. Vague, lack of knowledge of the specific and serious medical, psychological or social situation of the patient.	No feeling of health care practitioner being empathetic. Felt the health care practitioner was sent by more experienced senior health care
<b>Emotionally burdened expert</b>	Message delivered carefully. Strong personal feelings, very kind, sometimes tearful, too emotionally involved. Good ability to communicate.	Felt health care practitioner was emotionally strained but very considerate and understanding.
<b>Rough and ready expert</b>	Message delivered in short, explicit, concentrated way- and fast, without regard to timing or rejecting body language. Tough, hardhearted and devoid of any interpersonal skills but had medical experience and competence. <b>Example: “Given these facts, you have 3 months left”</b>	Felt health care practitioner had no interest in emotional state, and lacked respect. Felt health care practitioner believed patient would not know anything about her/his own illness.
<b>Benevolent but tactless expert</b>	Message delivered using distressing words, and information conveyed could be forced or interpreted to be very subjective. Competent, with a friendly and sympathetic attitude, but without the capacity to communicate well. <b>Example: “Well you have a malignant tumor, and it’s going to take your life”</b>	Felt health care practitioner was personable, but not sensitive to patient’s situation and reaction to the information.
<b>Distance d expert</b>	Message delivered fast and concisely, in a calm, objective and dominant manner. Theoretical knowledge of and experience in patients’ reactions, but interacts by distancing self from patient. Manipulates conversation in a manner that avoided deeper discussions. Lacks sensitivity, emotional competence, and communicative capacity.	Felt health care practitioner deliberately kept a distance. Felt health care practitioner was uninterested and did not care about the person behind the illness or her/his thoughts, hopes, or feelings.
<b>Empathic Professional</b>	Message delivered balancing medical competence and empathy for the patient. Capacity to read emotional state of patient. Interested in both physical and psychological concerns. Learns practical concerns important to the patient and assists her/him.	Felt health care practitioner accepted and understood concerns and feelings. Felt comfortable, confident and safe.

(Adapted from Friedrichsen, Strang, and Carlson, 2000)

## **Collaboration and Shared Decision Making Patient Centered Communication in End of Life Discussion**

Patient centered communication requires the establishment of a respectful relationship with the patient where common goals can be developed to guide the patient's course of treatment. It also demands open and honest communication as well as a clear understanding and respect for different perspectives.

Mast, Kindlimann, and Langewitz, in a 2005 study of health care practitioner style when breaking bad news, found that patients and their families were the most satisfied with health care practitioners who used a patient centered approach. Patient centered health care practitioners were collaborative, concerned with the patient as a person, provided the most appropriate information, offered hope, and were less dominant than their colleagues. Similarly, Shanawanti, Wenrich, Tobelli and Randall (2008) found that good health care practitioner communication and support improved the quality of care a patient received at the end of life and assisted in the reduction of depression and anxiety among both patients and their family members. Health care practitioners who elicited patients values and expectations, their preferences for care, and who provided support and guidance throughout the decision making process during end of life discussions, were more likely to experience less burnout. These health care practitioners also experienced less psychological morbidity, more satisfaction with their jobs and less work stress than colleagues who failed to use such an approach (Maguire and Pitceathly, 2002; Roter, Larson, Fischer, Arnold, and Tulsky, 2000).

Providing and receiving information that is perceived by both the health care practitioner and the patient as negative without examining the effect of the information, keeps the “elephant “ in the room and can lead to misunderstanding between the health care practitioner and patient, health care practitioner burn-out, patient dissatisfaction and litigation (Maguire, 1999; Feudtner, 2007). The good news is that there are strategies that health care practitioners can learn and use to facilitate open and collaborative communication with patients and their families.

### **Three Communication Skills**

There are three communication skills that are both necessary and helpful to health care practitioners in their discussions with patients and families. They have both verbal and non-verbal components, and are critical to the establishment and maintenance of a good relationship with the patient. The skills are:

1. The ability to distinguish between the intellectual and emotional components of what a patient says during the conversation and to respond empathically.
2. The ability to clarify any uncertainties or doubts related to:
  - a. The health care practitioner’s understanding of what the patient has said.
  - b. The patient’s understanding of what has been said, including the patient’s perception and knowledge about treatment options, as well as any psychosocial concerns related to the patient’s emotions and quality of life.
3. The ability to listen more and talk less.

At face value these skills seem straightforward. However, just as health care practitioners must learn and practice clinical techniques to become proficient in a particular area of practice, communication skills need to be learned and practiced before one is adept at using them.

Understanding and applying these skills effectively in interactions with patients saves time, reduces misunderstandings, increases patient satisfaction, reduces health care practitioner frustration, and as well, increases and improves patient outcomes (Halpern, 2007). Other benefits include:

- The development of trust and mutual respect between the patient and health care practitioner
- The disclosure of patient's concerns
- The reduction of tension during a difficult interaction
- The creation of a safe environment where treatment plans and goals can be discussed in an open and honest manner

### **The Discussion and the Environment**

Prior to and while engaging in a discussion about end of life decisions and care with a patient and family using the three communication skills, it is important that an environment is created that facilitates communication. Creating the environment is essential as it provides a space that will assist each participant with the capacity to focus solely on the discussion, and demonstrates to the patient and

family that the discussion is important. Constructing the “communication space” includes the following steps:

- Secure a private room (or area, if a room is not available) for the discussion
- Ensure a box of tissues is visible and nearby
- Avoid interruptions - pagers and cell phones should be turned off and phone calls should be held until the discussion is over
- Schedule enough time to ensure that the patient and family concerns have been addressed and that they understand the next steps that will be taken
- Set up the room/area in a way that allows everyone to sit down. Standing gives the impression of being in a hurry.

Another factor that is important to the creation and maintenance of a physical environment that facilitates communication is attention to and the use of non-verbal communication. It is often as important as verbal communication during a discussion about end of life treatment and care. And it is critical that a health care practitioner who provides information to a patient and family is aware of her/his non-verbal communication. The acronym SOLER stands for a method that a health care practitioner can use to monitor her/his non-verbal presentation throughout the discussion. Table Four outlines the method.

**Table 4: SOLER**

S	Face the patient squarely at eye level to indicate your interest in the discussion
O	Adopt an open body posture (do not cross your arms)
L	Lean toward the patient
E	Use eye contact to show that you are paying attention (do not look at your watch) the clock,
R	Maintain a relaxed body posture

(Back, Tulskey, Arnold, 2009)

After the environment has been created and the health care practitioner has decided the main points s/he wants to discuss with the patient and/or family, the discussion can begin. At the beginning of the discussion it is essential for the health care practitioner to initially assess the patient's understanding of where s/he is in the disease process. Once this information has been gathered, it is important for the health care practitioner to ascertain how much the patient would like to know about her/his condition. Some patients want explicit details, while other patients prefer a general overview. In the tables that follow, specific examples are provided on how to frame these first two questions.

## **A Note About Silence**

It is necessary to be aware that during a discussion about end of life treatment and care there may be periods of silence. Sometimes after a patient receives information that is life changing, the patient initially reacts with silence. Periods of silence can be uncomfortable for a health care practitioner who has given “bad news” to a patient. However, it is important for the health care practitioner to honor the silence.

During a period of silence the patient is attempting to make sense of the information that has just been relayed by their health care practitioner. The patient’s silence is frequently a response to their beliefs and values about the medical treatment they have received, and the expectations they have formed about their care/and treatment in relation to their disease. At the most fundamental level, the patient tries to construct meaning within the context of their personal belief system about the information they received immediately preceding the silence. And it is the silence that allows the patient to gather their thoughts, process the information and formulate questions. When the discussion begins again, it can be useful to ask the patient what they were thinking about during the interlude. Such a question demonstrates to the patient that the health care practitioner is comfortable with silences and cares about their well-being.

## **Communication Skill Characteristics**

The three skills previously outlined serve as the basis for patient centered communication and are based on the active listening, attending, and facilitative (empathic/reflective) concepts of communication. Table Five provides a broad overview of these concepts and illustrates the effect that the application of these skills has on patients and families during discussions about end of life decision-making. The skills are broken down into discrete steps that a health care practitioner can use as a guide.

**Table 5: Skills and Outcomes**

<b>Active Listening Skills (Empathic/Reflective Communication)</b>	<b>Attending Skills</b>	<b>Patient Outcome</b>
<p>Be attentive. Create a positive atmosphere through non-verbal behavior. Look at the patient and focus on the “here and now”.</p>	<p>Maintain eye contact. Pay attention to your body language. Open posture indicates your willingness to take the time to listen. Closed posture crossed arms, fidgeting indicates disinterest. Pay attention to patient’s body</p>	<p>Demonstrates to the patient that you are interested.</p>
<p>Listen to the patient, not merely their words, but the “feeling” content.</p>	<p>Identify the patient’s specific feeling.  Be able to acknowledge and reflect it back to the patient.  E.g. You seem shocked... You seem angry... You seem upset...</p>	<p>Demonstrates to the patient that you understand how s/he feels and that you care.</p>
<p>Show interest in what the patient is saying. Be a sounding board for the patient.</p>	<p><b>Use your own voices sparingly.</b> Use cues like nodding or “yes, um, huh” to let the patient know you are listening.</p>	<p>Demonstrates to the patient that you believe what s/he is saying is important.</p>
<p>Restate what the patient has said.</p>	<p>Mirroring/ Verbal tracking</p>	<p>Demonstrates that you understand what the patient has said and are</p>
<p>Clarify information that the patient has provided.</p>	<p>Use phrases such as “It sounds like you are saying ”.</p>	<p>Clarifies any misunderstandings about what the patient has said or wants relative to her/ his care and treatment and demonstrates that you care about understanding what s/he has said.</p>
<p>Be aware of your own opinions and feelings throughout the conversation. Body language and non-verbal communication are as powerful as verbal communication.</p>	<p>Self-monitoring</p>	<p>Demonstrates that you are non-judgmental.</p>
<p>After listening to the patient offer your views and work on a plan.</p>	<p>Throughout this process it is important to ensure that the patient understands, that you obtain her/his understanding and that you reflect back to her/him what has been said.</p>	<p>Demonstrates that you are working with the patient.</p>

## **Attributes of Questioning, Listening and Responding to Patients**

Specific communication attributes that health care practitioners use when questioning, listening to, and responding to patients and their families during conversations about end of life care and decision making can have a variety of both helpful and unhelpful qualities. Some attributes facilitate meaningful conversation, where disagreements concerning a patient's treatment and care are worked out, result in a plan of care that is acceptable to the patient and their family, and provide the quality of life that the patient has requested at the end of her/his life. Other communication attributes close the door on a meaningful conversation and can result in a poor quality of life for a patient at the end of life, a patient and family's dissatisfaction with the health care practitioner, and litigation. Talking, seeing and hearing are all important to the process, but listening and understanding are essential to communication. A health care practitioner's body language, what they say to a patient and how it is said, can be the seminal point in a patient's quality of life at the end of life.

Table Six provides an outline of types and elements of communication attributes that can facilitate or act as a barrier during a health care practitioner's questioning, listening and responding to a patient and family during a discussion about end of life care. Specific examples are provided to illustrate the influence each attribute has on a patient during a discussion about end of life decision making.

**Table 6: Questioning, Listening, and Responding**

<b>QUESTIONING</b>		
<i>Type of question</i>	<i>Attributes</i>	<i>Example</i>
Closed ended	Focus on one specific problem and limit choice of response Yes /No questions or questions that require a single word	How old are you? Do you have trouble swallowing?
Open ended	Broad in scope and allows patient to answer in any way s/he chooses	How are you feeling? What do you think the problem might be?
Biased	Judgmental statements phrased as a question	Don't you think your cough may be related to the fact that you've smoked for the past 25 years?
<b>ACTIVE LISTENING</b>		
<i>Elements</i>	<i>Characteristics and Approach</i>	
Do not interrupt the patient while s/he is talking	Do not talk over the patient Wait for the patient to finish speaking before beginning the next part of the conversation.	
Do not answer phone or pager during conversation	Turn off phone or pager. Answering the pager or phone sends the message to the patient, that the health care practitioner really isn't interested in the conversation.	
Sit down when giving information to patient.	Sit facing the patient at her/his eye level. Demonstrates that the conversation is important, you are providing time for it, and you are listening.	
Encourage the patient to talk	Maintain eye contact as the patient speaks. Nod, smile, and lean forward. Use phrases like Yes, hmm. Tell me more, I see.	
Tolerate short silences	Occurs when patient is overwhelmed with feelings or thinking about something important to her/him in relation to the news.	
Listen for the hidden question	Patient asks question in soft voice while you are talking. When done with your sentence say something like, "I'm sorry, you were about to ask me something."	
<i>The 3 Rs</i>	<i>Approach</i>	<i>Example</i>
Repetition	Use a couple of key words from the patient's last sentence in your first one to demonstrate that you are listening	Patient-"After I take the pill, I feel dizzy" Health care practitioner-"The pill makes you feel dizzy?" Patient-"Yes"
Reiteration	Repeat what the patient has told you in your own words	Health care practitioner-"You seem to be getting some lightheadedness from the pill"
Reflection	Takes listening one step further and demonstrates that you have heard and interpreted what the patient has said.	Health care practitioner-"If I understand you correctly, you're telling me that you are having a difficult time functioning after taking the pill"



## A Mnemonic for Empathic/ Reflective Communication And a Patient Support Triad

Listening for patients and family member emotions, offering hope, and responding to patients empathically requires patience, skill and practice. The mnemonic in Table Seven is of assistance to individuals when first learning reflective/active listening communication skills. It reminds the health care practitioner to:

- Name the patient’s emotion
- Clarify her/his own understanding of what the patient is concerned about
- Show respect for the patient verbally
- Let the patient know that s/he will not be abandoned
- Explore any concerns that the patient may have.

**Table 7: The NURSE Mnemonic**

NURSE	EXAMPLE
N= Naming	“It sounds like you are worried that the cancer is back”
U= Understanding	“My understanding is that you are concerned about the effect that more treatment will have on your family”
R=Respecting	“It is impressive to me how well you’ve been able to take care of your family during your illness”
S=Supporting	“No matter what happens, I’ll be with you throughout this illness”
E= Exploring	“Can you tell me what is the thing you are most worried about with the treatment”

(Adapted from Fischer, Tulsy & Arnold, 2000)

Similar to the NURSE mnemonic, the Support Triad in Table Eight provides examples of empathic statements, exploratory questions and validating responses. A combination of questions and statements similar to the examples in Table Eight can be used to provide support to patients and families in their discussion about end of life care and decision-making.

**Table 8: The Support Triad**

<b>Empathic statements</b>	<b>Exploratory questions</b>	<b>Validating responses</b>
"I can see how upsetting this is to you"	"How do you mean?"	"I can understand how you felt that way"
"I can tell you weren't expecting to hear this"	"Tell me more about it"	"I believe everyone would have a similar reaction"
"I know this is not good news for you"	"Could you explain what you mean?"	"You were perfectly correct to think that way"
"I wish the news were different"	"Could you tell me what you are worried about"	"It seems like you've thought things through very well"
"I was also hoping for a better result"	"You said you were concerned about your kids, tell me more"	"Many other patients have had a similar experience"

(Baile , Buckman, Lanzi et al,2000)

### **Communication Strategies**

There are three major segments that relate to discussions about breaking bad news and end of life decision making. The segments include **preparation** (health care practitioner preparation, environmental preparation and patient/family preparation), **information sharing**, and **follow-up** (Hallenback, 2003). Each of these segments is further broken down into distinct steps in the communication strategies.

Table Nine is a compilation of the strategies that were developed by health care practitioners with expertise in medical communication. Although the strategies that are outlined are very similar to one another, all are offered, as there are some subtle differences between each of them. These strategies have been used as a basis for the development of other guidelines tailored to end of life decision making with patients and families, as well as for transitioning the patient from curative to palliative care. All of the strategies use the empathic/reflective and facilitative concepts of communication and generally follow the same format.

**Table 9: The Communication Strategies**

A Girghis PhD & R. W. Sanson- Fisher PhD	Peter Maguire, MD Breaking Bad News	Walter Baille, MD Robert Buckman, MD <i>The SPIKES protocol</i>
Ensure privacy and adequate time	Ensure Privacy and time	<b>SET</b> up the interview- ensure privacy and time
Assess patient understanding	Elicit the patient's main problems and the patient's perceptions of problem ( <i>can use euphemisms when patient has no awareness of diagnosis to see if s/he is ready to hear full diagnosis</i> )	Assess the patient's <b>PERCEPTION</b> of his/her problem
Provide information about diagnosis and prognosis honestly and simply	Be honest and tailor information to what the patient wants to know; checking his or her understanding of the information conveyed	Obtain the patient's <b>INVITATION</b> to disclose the details of his/her illness
Encourage patient to express feelings	Elicit the patient's reactions to the information given and his or her main concerns	Give <b>KNOWLEDGE</b> and information to the patient in small amounts, avoid medical jargon, check frequently for patient understanding
Be empathic	Explore patient concerns and the physical, emotional and social impact of the patient's problems on the patient and family	Address the patient's <b>EMOTIONS</b> . Empathize and explore patient's expressed emotions Respond to the patient with empathic responses. E.g. "I can see you weren't expecting this news... I can see this is really difficult for you..."
Give broad and realistic time frame concerning prognosis	Determine how much the patient wants to participate in decision making (when treatment options are available) and arrange a time to meet again	<b>SUMMARIZE</b> and plan for future care/treatment. Close with a clear verbal contract. You'll do __; I'll do __; We'll re-evaluate ____

**Table 9: The Communication Strategies Continued**

<p><b>Robert Buckman, MD</b> <b>The CLASS Protocol</b></p>	<p><b>James Hallenback, MD</b> <b>Stamford University</b></p>
<p>Physical <b>CONTEXT</b> or setting- ensure</p>	
<p><b>LISTENING</b> Skills-Use reflective communication Determine patient’s perception of her/his illness. (Health care practitioners often interrupt patients after 19 seconds) 90% of the time patients finish speaking in less than two minutes.</p>	<p><b>Prepare self, patient and environment.</b></p> <ul style="list-style-type: none"> <li>• Decide phrases to use, practice giving news, &amp; prepare emotionally for the discussion.</li> <li>• Ensure setting is private and enough time has been allotted.</li> <li>• Establish what/patient /family knows, how much they want to know, and how they would like the information delivered.</li> </ul>
<p>Provide information clearly and honestly, in small increments <b>ACKNOWLEDGE</b> patient emotions and explore them. Respect the reactions the patient expresses. Explore patient emotions. State what is covertly obvious. Your acknowledgement is of the patient’s reaction to the information, not of your opinion about the seriousness. This is not a “routine” matter to the patient</p>	<p><b>Provide information</b></p> <ul style="list-style-type: none"> <li>• Establish rapport with patient/family member</li> <li>• Give an advance warning</li> <li>• Provide information honestly and clearly in language that the patient/family member understands</li> <li>• Observe and respond to medical concerns and emotional reactions.</li> <li>• Clarify any ambiguity</li> </ul>
<p>Provide a <b>STRATEGY &amp; SUMMARY</b> for what has been said. Encourage patient/family input into treatment plan. Refer to other resources as appropriate</p>	<p><b>Follow up</b></p> <ul style="list-style-type: none"> <li>• Set concrete goals.</li> <li>• Connect patient/family with support</li> <li>• Arrange follow up meetings.</li> <li>• Convey commitment and non-abandonment</li> <li>• Communicate with team.</li> </ul>

(Adapted from Girgis, A., & Sanson-Fisher, R., 1998; Maguire, 1998; Baile et al., 2000; Buckman, 2003 & Hallenback, 2003)

## **Trust, Empathy and Hope**

Trust, empathy and hope are the core of patient centered communication. Trust is the patient's conviction that the health care practitioner will always act in their best interest. A health care practitioner secures a patient's trust by establishing rapport, and once established, by building a relationship with the patient.

Empathy is at the heart of developing and establishing trust. It requires the health care practitioner's ability to read the patient's emotional state and proficiency in the skills of attending and active listening. It demands consciously listening for the patient's affective concerns that may be buried in anger, despair, or clinical demands and consciously developing an interest and understanding of the patient's perspective. (Halpern, 2007).

Hope is perhaps the most difficult emotion that a health care practitioner must struggle with when relaying information to a patient that will be viewed as negative to the patient's current or future circumstances. A health care practitioner must convey information to the patient about their disease process and prognosis without being too blunt, and also avoid giving the wrong impression about the seriousness/prognosis of the disease. Whitney, McCullough, Fruge, McGuire, and Volk (2008) suggest that it is important for a health care practitioner during a "bad news" conversation with a patient to offer the patient hope by focusing on concrete goals in the management of the patient's disease that can be accomplished; rather than goals of cure and a long life. Such goals give the patient some control over an uncontrollable process, and are of assistance to the patient's well-being. In Table Ten, Tulskey (2005) using many of the communication characteristics and strategies previously outlined, offers examples in establishing trust, offering hope and communicating collaboratively with patients.

**Table 10: Trust, Empathy & Hope**

BUILDING TRUST	ATTENDING WITH EMPATHY	COMMUNICATING WITH HOPE
<p><b>Encourage patients and families to talk</b>  <b>Examples:</b>                      “Tell me what you know about your illness”                      “I’m sure being sick is a lot for you to deal with so quickly. How are you coping with it?”  <b>New Patient</b>                      “We’ve just met, and there is a lot going on with you right now. To help me get to know you better can you tell me about your life outside of here?”</p>	<p><b><u>Acknowledge the emotion</u></b>  <b>Examples:</b>                      “Is talking about these issues difficult for you?”                      “I wonder if it sometimes feels overwhelming.”                      “Making these decisions (on behalf of _____) isn’t easy.”</p>	<p><b><u>Hope for the best but prepare for the worst</u></b>  <b>Example:</b>                      “Have you thought about what would happen if things don’t go as you’d like?”                      “Sometimes having a plan that prepares you for the worst, helps to focus on what you hope for the most”</p>
<p><b><u>Do not contradict/put down other practitioners that have cared for the patient/ but recognize the patient’s concerns.</u></b>  <b>Examples:</b>                      “I hear you didn’t feel heard by Dr. Doe or that he was listening. I’d like to make sure you have a chance to tell me all of your concerns.”                      “It sounds like Dr. Doe left you feeling hopeful for a cure, I’m sure he cares about you, and it would have been terrific if things had gone as well as he wished”</p>	<p><b><u>Identify Loss</u></b>  <b>Examples:</b>                      “I bet it’s hard to imagine leaving your _____”                      “I imagine it’s hard not to be able to walk in the woods any more, you’ve told me how you loved doing that”                      “ I sense it must be difficult to imagine life without _____, I can see how close you are”</p>	<p><b><u>Reframe Hope</u></b>  <b>Examples:</b>                      “I know that you are hoping that your disease will be cured. Are there other things you want to focus on?”                      “I want the disease to stay in remission too, if we can’t make that happen, what other shorter term goals might we work on?”</p>
<p><b><u>Be Humble</u></b>  <b>Example:</b>                      “I really appreciate what you’ve shared about the side effects of the medication. It’s clear the approach I suggested won’t work for you”</p>	<p><b><u>Legitimize the feeling</u></b>  <b>Examples:</b>                      “It’s very common for someone in your situation to have a tough time making these decisions- it can feel like a huge responsibility”                      “Of course talking about this makes you feel sad- it wouldn’t be normal if it didn’t”</p>	<p><b><u>Focus on the Positive</u></b>  <b>Examples:</b>                      “We’ve been talking about some treatments that are really not going to be effective for you. But there are a lot of other things we can still do to help you- let’s focus on those”                      “What sorts of things are left undone for you? Let’s talk about how we might be able to make these happen.”</p>
<p><b><u>Demonstrate Respect</u></b>  <b>Example:</b>                      “I am so impressed with how involved you’ve been with your _____ throughout this illness. I can tell how much you care about _____.”</p>	<p><b><u>Offer Support</u></b>  <b>Example:</b>                      “No matter what is ahead, I’ll be there with you”</p>	

(Adapted from Tulsy, 2005)

## **Family Centered Communication: When Families and Loved Ones**

### **Make Decisions on Behalf of the Patient**

Discussions with family members and loved ones, for myriad reasons can be particularly taxing for health care practitioners. Family members may have disparate views about the care and treatment of the patient. Every family member brings their unique relationship to the patient and their own emotional needs to the discussion. And all family members have a particular role within the family unit that may have changed with the onset of the patient's disease. Families are distinct entities with their own culture and way of communicating.

It is important for the health care practitioner to create an environment for communication that is "neutral" and to act as a facilitator in this collaborative decision making process (Back, Arnold, Tulsky, 2009). In creating a neutral environment for the discussion it is imperative to have an idea about how the family functions and the patient's role within the family. At the outset of the discussion ask each family member about her/his relationship and quality of her/his relationship to the patient. Ask how decisions are usually made within the family's constellation. Questions can be very simple, such as: "Can you tell me a bit about your relationship? "Do you get along?", "Who makes the decisions?", "How could you make a medical decision that you would be good with?", "Is there anyone that is not here right now that should be involved in the process?"

It is also essential for a health care practitioner who is facilitating a family discussion to avoid taking sides with one or more family members. Taking sides can add additional tension to a situation that is already emotionally charged and lead to further dissension and mistrust between the family and toward the health care practitioner

Last and equally as important as having some understanding of the patient's role and family dynamics, it is essential that the health care practitioner is empathetic to family members' concerns. As empathy builds and fosters a health care practitioner's relationship with a patient, it is also necessary in building a relationship with the patient's family. Empathy assists in both creating and sustaining a neutral environment in which open and honest communication can occur. Empathy requires proficiency in the skills of attending and active/reflective listening. This includes the health care practitioner's ability to recognize her/his own emotions and simultaneously using her/his skills to track the family's emotions. In other words, the health care practitioner must recognize and adjust to the family's verbal and non-verbal emotional messages, be receptive to and understand the family's feedback and respond to those concerns in an empathetic manner.

Table Eleven offers a mnemonic to use in end of life discussions with families, which is valuing and in turn understanding the patient /family. Table Twelve offers a family centered strategy which has many similarities to the strategies outlined in Table Nine on breaking bad news.

**Table 11: The VALUE Mnemonic**

V= <b>Value</b> statements by family members
A= <b>Acknowledge</b> family member emotions
L= <b>Listen</b> to family members
U= <b>Understand</b> who the patient is as a person and how decisions are made in the family
E= <b>Elicit</b> questions from family members

(Curtis & White, 2008)

**Table 12: Family Discussion Strategy for Collaborative Decision Making**

STEP	EXAMPLE
<p><b>Prepare for the meeting</b>            Allow adequate time            Arrange for a private meeting space            Invite all family members            Meet/talk with all of the patients health care practitioners prior to the meeting to ensure that a consistent message will be given to the family</p>	
<p><b>Introduce all participants and the purpose of the meeting</b>            Ask family members to introduce themselves and state their relationship to the patient.            Provide an overview of the purpose of the discussion</p>	<p>“I’m Dr. Doe and I am _____’s coordinating health care practitioner            Can each of you please tell me your name and your relationship to _____”            “I want to tell you how _____ is doing medically. I also want to make sure that you are clear about what we are doing and what we are watching for. Finally I want to learn from you _____’s values and goals so that we can make decisions that _____ would want if _____ was still able to make decisions. Before we begin is there anything else you want to make sure we discuss?”</p>
<p><b>Find out what the family knows and their expectations</b>            What have they been told?            What have they seen?            Do they want general information or specific information about their family member?</p>	<p>“Can you each tell me what you know about _____’s illness?”            “What do you think is happening with _____?”            “Some families want detailed information of their loved one’s situation, other families prefer a general overview. Some families like statistical information. What kind of information would you all like?”</p>
<p><b>Describe the clinical situation</b>            Provide the big picture            Skip detailed pathophysiology and provide an explanation of their loved one’s current situation and what has been done for her/him to date.            When finished, check for the family’s understanding of what you’ve said.</p>	<p>“One of the complications of _____’s disease is pneumonia. _____ has pneumonia now and we have been treating the infection for the past couple of days with medication that usually responds well to this type of situation. I wish I could tell you this is happening in _____’s situation and I’m sorry but _____’s condition has worsened.”... Does what I’ve said make sense? Is there anything that’s not clear?”</p>
<p><b>Ask family members for their questions and concerns.</b>            Make sure all questions are answered            Make sure the affective content of family members concerns are acknowledged            Do not take sides            If only one or two family members are sharing their concerns, invite other family members to talk about their concerns.</p>	<p><b>Doctor:</b> “I’ve just given you a picture of _____’s medical situation. Can you tell me what other questions or concerns that you have?”  <b>Family member 1</b> “is _____ going to die?”  <b>Family member 2</b> “_____ isn’t dying, right doctor? _____ has just had a little down turn, right?”  <b>Family member 3</b> “I’m really scared w o n ’ t make it?”  <b>Doctor:</b> It sounds like you are all upset about _____’s situation. and it seems like you all deal differently with uncertainty.  <b>Family members 1,2,3, acknowledge that they are upset and deal differently with uncertainty</b></p>

**Table 12: Family Discussion Strategy for Collaborative Decision Making Continued**

STEP	EXAMPLE
<p>Explore the patient's values and how they influence decision making</p>	<p><b>Doctor:</b> "If _____ was here in this room with us right now, can you tell me what s/he would say about her/ current condition?"  <b>Family member:</b> "I can tell you _____ would be embarrassed about being hooked up to so many machines and tubes and wouldn't like it. _____ wouldn't want to be dependent upon machines... but please you can't take her/him off of them now"  <b>Doctor:</b> "I can see this is very difficult for you. And I really appreciate you telling me what _____ would say if s/he was in this room right now, so we can respect _____ values. I know it must be really hard when you just want someone you care about to stay alive".</p>
<p>Propose a goal for patient's care- reiterate importance of honoring patient's values</p>	<p><b>Doctor:</b> "Again I just want to say how much I appreciate what you've all said about _____. It gives me a better idea of _____'s views as an individual as well as your concerns. Thank you. I'd like to talk about some of the ideas I have for the next steps in _____'s care and get some input from all of you. Would that be ok?"  <i>(Health care practitioner then recaps situation and explains potential care and treatment as well as treatment that will be of little or no benefit to the patient)</i> <b>Note: The goal for care is often a negotiated agreement that with the patient's family/loved ones.</b></p>
<p>Provide a Concrete Plan</p> <ol style="list-style-type: none"> <li>A. Summarize both areas of an agreement and disagreement among family members/loved ones</li> <li>B. Reiterate diagnosis</li> <li>C. Focus on the goal of care / treatment.</li> <li>D. Discuss prognosis and acknowledge uncertainty. Discuss the fact that how the patient responds to care/treatment may affect future decisions regarding treatment</li> <li>E. Provide Support-Hear what the family has to say and identify their feelings. A health care practitioner does not necessarily have to agree with the family, but s/he does have to listen to what the family is saying and address their concerns.</li> <li>F. Present a plan- The presentation of a plan provides the family with a map of what will be done for the family's loved one's immediate future and that their loved one has not been abandoned.</li> <li>G. Make a contract to follow up</li> </ol>	<p><b>Doctor:</b> "I've talked with each of you and know this is a very difficult time. It's been 3 days since we started giving _____ the antibiotics, and as you know right now the nasal oxygen is not supplying enough air to her/his lungs. So I have suggested that we place _____ on a ventilator for now and continue with the antibiotics to see if they help. Everyone is in agreement with this plan, right?"  <b>Family member spokesperson:</b> Yes.  <b>Doctor:</b> "I've also explained, there are risks to keeping someone as sick as _____ on a ventilator for more than a few days and that we could make a small cut in _____'s windpipe and attach the ventilator to _____'s windpipe, but that it is risky because _____'s resistance to infection is low and there is a high probability that _____ would get an infection. Some of you would be willing to go ahead with this procedure."  <b>Family member spokesperson:</b> "Yes."  <b>Doctor:</b> "We aren't at that point yet, but you all may want to talk about this procedure some more. _____ has pneumonia as a complication of her/his disease. I should know if the antibiotics are helping at all in the next couple of days. You all have told me that _____ is a dignified person. Our goal is to keep _____ as comfortable as possible and see if the antibiotics help. I will let whoever is here when I'm doing my daily rounds what is happening. We'll all meet together again on Friday. Before we leave, do any of you have any questions?"</p>

(Adapted from Back, Arnold & Tulskey, 2009)

## **Conflict in End of life Decision Making**

Treatment and care goals at the end of life generally lie along a continuum between two points. At one end of the continuum, maximum support and care is provided to the patient for her/his comfort and dignity, and at the other end diagnostic and therapeutic care is provided to maintain the patient's life (Lang and Quill, 2004). Both goals are appropriate at different points in the patient's disease process, and the majority of patients and families understand the continuum. However, with the arrival of medical technology in the latter part of the 20<sup>th</sup> century, patients and families now have a broad array of choices that can prolong life. These choices include procedures such as tube feeding, mechanical ventilation, dialysis and cardiopulmonary resuscitation. While the health care practitioner may understand that these procedures often have little or no benefit to the patient, and that a procedure for each complication from the patient's disease process only changes the patient's functioning, and does not stop the outcome, some patients/families place tremendous trust and belief in the power of them.

When the patient's health care practitioner and team have taken all curative or restorative measures to return a patient to functioning at a capacity that s/he would want, and the disease has prevented her/his return to her/his former capacity, it is critical that the health care practitioner make recommendations regarding a care plan for the patient with the patient, or if the patient no longer has decisional capacity, with the family that considers the patient's values and preferences. Sometimes the plan that a health care practitioner recommends can be considerably different from the patient or family's wishes. This is especially true

when the patient or family have indicated the desire for “everything”. Often this can create conflict between the health care practitioner and patient, family members within the family’s structure and / or with the health care practitioner. This juncture can be extremely frustrating for those involved in the process and a win-lose attitude can hinder an appropriate course of action. In an attempt to resolve differences it is important for the health care practitioner to honor the patient’s values and wishes, and through negotiation with the patient and/or family come to consensus and agreement on a plan. It is also important to know that the request for “everything” is often specific to a particular set of circumstances. Prior to developing orders to implement procedures or treatments that encompass “everything” the health care practitioner should explore with the patient or family what “everything” means.

Quill and Lang (2004) and Quill, Arnold and Back (2009) offer the following points that can be of assistance to health care practitioners in situations where there is conflict or where the patient or family wants “everything”:

1. Before proposing a plan and using effective listening and reflective communication skills, determine the accuracy of the patient and/or family’s knowledge about the patient’s condition.
2. Determine the level of the patient/family’s acceptance about the patient’s current condition.
3. With the patient/family come to a consensus about the patient’s prognosis. Determine what “everything” means.
4. Frame the importance of survival versus the importance comfort at the end of life equally. (Discuss all choices –including hydration/nutrition and mechanical ventilation.)

5. Obtain patient's values, preferences and beliefs concerning care/treatment and quality of life from the patient, or family if the patient no longer has decisional capacity.
6. Discuss how to make decisions. Propose a "philosophy of treatment" based on what the patient or family believes the patient would want.
  - a. Care/treatment that would provide maximum relief from patient's pain but may unintentionally limit patient's life's time.
  - b. Care/treatment that has a realistic chance of prolonging patient's life's time, but not if it would increase patient's pain/suffering.
  - c. Care/treatment that has a realistic chance of prolonging patient's life's time, but may cause some increase in pain/suffering.
  - d. Care/treatment that has a realistic chance of prolonging patient's life's time, even a small amount of time, regardless of the effect on patient's pain/ suffering.
  - e. Care/treatment that has any possible potential of prolonging patient's life's time, even a small amount of time, regardless of the effect on patient's pain/ suffering
7. Make a recommendation for a plan based on the patient's values, preferences and beliefs.
8. If there is disagreement, negotiate differences. Attempt to find a middle ground and brainstorm possible solutions. An example would be a time limited trial of antibiotics and a mechanical ventilator.
9. Sometimes the disagreement cannot be resolved. When a patient or family want every possible procedure or treatment to prolong a patient's life's time, then the health care practitioner should honor, acknowledge and adhere to the request. At this point the health care practitioner should also refrain from discussing procedure/treatment limitations unless the patient or family brings it up.
10. Last, find other patient centered goals to work toward and use clinical judgment to limit treatment that does not define patient goals. Quill, Arnold, and Back use the example of CPR for a patient who does not have a DNR order. They suggest a harm reduction strategy and offer the following example: "stopping CPR after one cycle if the patient is unresponsive, because success is highly unlikely"... "this allows the family to know everything has been done, and avoids the ordeal of prolonged CPR without the prospect of recovery" (p. 348)

### **Sensitive Statements and Patient/Family Perception**

End of life discussions are difficult for everyone involved. Patients and families are particularly sensitive to verbal and non-verbal communication during these conversations. Body language, active listening, the use of empathic responses, and the clarity of the information that is relayed all contribute both to the patient and her/his family's satisfaction. Word choice is also an integral part of the health care practitioner's message when conveying negative information to a patient or family member. What the health care practitioner says is as important as how it is said. Table Thirteen provides examples of phrases that can easily be misunderstood, the patient's/family's possible perception, and alternative phrases.

**Table 13: Sensitive Statements**

Phrase	Possible Perception	Alternative
<p>“There’s nothing we can do for you”                      “There’s nothing we can do for your husband”</p>	<p><b>Abandonment:</b> “My physician doesn’t want to see me anymore”                      He’s going to suffer, and they don’t care about him, they only care about fighting the disease</p>	<p>“We can offer many options to control your symptoms and make you feel better.”                      “We need to change your husband’s goals of care. We can’t cure him, but that doesn’t mean we can’t help him.”</p>
<p>“It’s time to think about withdrawal of care.”                      “It’s time to think about withdrawing care</p>	<p><b>Cessation of care:</b> “My physician doesn’t want to care for me anymore.”                      They are giving up and they don’t care</p>	<p>“Do you think that it is time to consider a different type of treatment that focuses on your symptoms? I’ll be here with you no matter what you decide.”                      “Your husband is too ill to get better; we need to focus our efforts of making the most of the time he has left.”</p>
<p>“Do you want us to do everything that we can to keep you alive (e.g., artificial life support)?”                      Do you want us to do everything to keep your husband alive?</p>	<p><b>Cessation of appropriate care:</b> “If I don’t have them do everything, I won’t get good care.”                      “If I don’t have them do everything, it will be my fault if he dies”  <b>False hope:</b> “Since they’ve asked me about doing everything, he’ll get through this.”</p>	<p>“If you become extremely ill, would you want to be placed on artificial life support, or would you prefer a natural death?”                      “Your husband is very sick. If he was with us right now can you tell me what he would say? It will help me understand better what he would want us to do in this situation.”</p>
<p>“You’ve failed the treatment”.                      “your husband’s failed the treatment”</p>	<p><b>Personal failure:</b> “I’ve disappointed my physician.”                      “They are blaming my husband for this!! “</p>	<p>“The cancer has not responded to the treatment as we had hoped. How are you doing?”                      The tumor has not responded to the treatment.” I’m sorry; I wish the news were different.”</p>
<p>“Let’s stop (heroic, aggressive or active) treatment”</p>	<p><b>Abandonment, Cessation of any care, failure:</b> “I wasn’t able to fight it off so they’ve given up and are waiting for me to die. They don’t care”</p>	<p>“You have fought hard with us to beat this, despite all of our best efforts we can’t cure or arrest this disease.. When the disease doesn’t respond to treatment and all the side effects that come with it, it is really hard on everyone, especially on you and your loved ones. I really wish I had better news. I can promise we will do everything we can to make you as comfortable as possible.”</p>
<p>Do you want us to do CPR?</p>	<p><b>False hope:</b> CPR always works</p>	<p>“Tell me what you know about CPR?” “CPR is most helpful to patients who are relatively healthy and only then 1 in 3 patients live.” Your husband’s lungs are failing, and he is getting dialysis because his kidneys aren’t working. If his heart stopped, it would because his organs are failing and he is dying. Although I wouldn’t recommend CPR, I would like to continue what we are doing right now.”</p>
<p>“I think you should consider hospice.”</p>	<p><b>Despair and hopelessness:</b> “I’m going to die soon.”</p>	<p>“I want to provide intense, coordinated care with a team of professionals who will treat your symptoms and help you stay comfortable.”</p>

(Levetown and the Committee of Bioethics, 2008; Metzger, Q. N., August, K. J., Srinivasan, M., Liao, S., & Meyskens, F. L., 2008)

## **Cultural Considerations**

Cultural factors are an important consideration in discussions with patient and families about end of life care and treatment. A person's culture can play a significant role in shaping her/his values, actions, and beliefs about health and medical care. At times, patients and families have certain cultural expectations about health care. In order to provide effective care and treatment, the patient and family's expectations must be attended to and cannot be ignored.

While it is helpful to have an idea of a particular group's cultural norms, it is important to remember that the patient is an individual, and ascribing a specific set of cultural traits related to health and disease that is based on the patient's religion, ethnicity or nationality, without understanding who the patient is, can be counterproductive to the creation of an appropriate care/treatment plan. Most important to a patient's care and treatment at the end of life is a health care practitioner's understanding of the patient's physical, social and emotional experience in relation to her/his disease, and the impact of the meaning of that combined experience on her/his life.

Kleinman (1998) suggests that health care practitioners talk about disease in a sector specific language of biological functions and behavior; whereas patients and families, even when they incorporate terms such as "disease" from the medical sector, talk about sickness in a culture wide language of experience". In bridging this gap, Kleinman (2006) suggests using an explanatory approach with the patient and /or patient's family. This approach assists the health care practitioner in the development of an understanding of the patient within her/his local world. Through the development of some understanding of the patient and family's culture, the

health care practitioner is better able to negotiate a course of treatment and care.

Table Fourteen outlines the protocol and Table Fifteen offers a mnemonic to assist in interviews with patients and families.

**Table 14: Toward Understanding: An Explanatory Approach**

Step	Example	
<p>Ask about ethnic identity and determine whether it is important to the patient's sense of self.</p> <p>Acknowledge and affirm a person's experience of ethnicity and illness.</p> <p>This enables a respectful inquiry into the other person's identity.</p>	<p>How should I give you/ family information about _____?</p> <p>Who should I share the information with?</p> <p>Who makes decisions?</p> <p>Are there any topics that should not be directly discussed in your family?</p> <p>Let the patient /family know that there you may say something that is not culturally appropriate and if that happens to let you know</p>	
<b>THE ILLNESS NARRATIVE</b>	<b>QUESTIONS FOR THE PATIENT</b>	<b>QUESTIONS FOR THE FAMILY</b>
<p>Conduct an illness narrative to acquire an understanding of the meaning of the illness in relation to the patient/family's local world.</p> <p>Evaluate what is at stake for the patient and family as they face the end of a disease process.</p> <p>The evaluation can included closerelationships, material resources, and religiouscommitment, social standing, etc.</p>	<p>What do you call this problem?</p> <p>What do you believe is the cause of this problem?</p> <p>What course do you expect it to take?</p> <p>How serious is it?</p> <p>What do you think this problem does inside your body?</p> <p>How does it affect your body and your mind?</p> <p>What do you most fear about the treatment?</p>	<p>What do you call the problem?</p> <p>What do you think has caused the problem?</p> <p>Why do you think it started when it did?</p> <p>What do you think the sickness does? How does it work?</p> <p>How severe is the sickness?</p> <p>Will it have a short or long course?</p> <p>What kind of treatment do you think the patient should receive?</p> <p>What are the most important results you hope s/he receives from these treatments?</p> <p>What are the chief problems the sicknesshas caused?</p> <p>What do you most fear about this condition?</p>
<p>Consider the ongoing stresses and social supports that typify the patient and family situation and record the main problems associated with the illness and its treatment. E. g.. anxiety, work, money and any interventions to improve the situation-referrals to social service, psychological services, alternative and complementarytherapies etc.</p>	<p>What do you most fear about this condition?</p>	<p>What do you most fear about this condition?</p>
<p>Examine the patient/family culture in terms of its influence on clinical relationships.</p>	<p>Step outside of the box- from the information gathered determine what the barriers are and with the patient /family develop an appropriate plan of care.</p>	

(Adapted from Kleinamn, 2006; Leketown & the Committee on Bioethics, 2008)

**Table 15: The Ethnic Mnemonic**

<b>E: <i>Explanation</i></b>	What do you think may be the reason you have these symptoms? What do people important to you say about these symptoms? Do you know anyone else who has had or who has this kind of problem? (If patient cannot offer explanation, ask him/her what most concerns him/her about the problem.)
<b>T: <i>Treatment</i></b>	What kinds of medicines, home remedies, or other treatments have you tried for this illness?
<b>H: <i>Healers</i></b>	Have you sought any advice from clergy, spiritual leaders, friends, or others for help with your problems? Can you tell me about it?
<b>N: <i>Negotiate</i></b>	Negotiate options that will acceptable to you and your patient and that do not contradict, but rather incorporate, your patient's beliefs
<b>I: <i>Intervention</i></b>	Determine an intervention with your patient. This may include incorporation of alternative treatments, spirituality, and healers, as well as other cultural practices (e.g., foods eaten or avoided both in general and when sick).
<b>C: <i>Collaboration</i></b>	Collaborate with the patient, family members, other health care team members, healers, and community resources.

(Adapted from Levin, Like & Gottlieb, 2000)

## **A Note About Translators**

Non -speaking English patients and families and the health care team can benefit greatly from the services of a professional. If possible professional translators should be used to communicate with non- English speaking patients and their families. Using a family member to translate during a discussion about end of life treatment and care is ill advised. The family member who has been called upon to translate is often emotionally distressed and while the health care practitioner is conveying the information, s/he is translating and simultaneously attempting to absorb and make sense of the information. Similarly, office or hospital staff that is called on to translate may not have the fluency in English to translate effectively, and important information can be lost in the process. A professional translator is a neutral party in an emotionally charged situation. In addition to being fluent in a patient's language, a professional is often aware of the patient's cultural norms, and in most instances can quickly develop some type of rapport with the patient and/or family. Having a rapport with the patient or family better assists the health care practitioner in her/his task of conveying negative information and developing an appropriate plan of care.

## **Dos and Don'ts**

Table Sixteen reiterates some of the key communication points in discussion with patients and families about end of life decision making.

**Table 16: Communication Reminders**

DOs	DON'Ts
Do ask the patient her/his current understanding of her/his disease	Don't assume the patient has a clear understanding of her/his condition.
Do ask the patient how much s/he wants to know about the disease E.g.: If this turns about to be serious, are you the type of person who wants to know exactly what is going on? Would you like me to tell you the details about your diagnosis? How much would you like to know about your condition? Shall I outline your condition for you or shall I give you the full details about what is going on?	Don't assume the patient wants to know about her/his disease.  In situations when the patient doesn't want to know, acknowledge the patient's preference with a phrase like "That's fine , if you change your mind or have any questions in the future , just ask me, I'm here"
Do tell the patient what you will be communicating. E.g. The diagnosis, prognosis, treatment options, etc. State information in clear and plain language, and ask the patient if s/he has understood what you have said. Consider asking the patient to restate what you have said to make sure s/he has understood.	Whenever possible, don't use acronyms or medical jargon. It "excludes" the patient from the conversation and further clouds the understanding that s/he has about her/his medical condition during an emotionally charged situation.
Do always try to identify and acknowledge your own and the patient's strong emotions	Don't ignore your own or the patient's strong emotions .Until emotions are acknowledged, the situation will be awkward and communication will be difficult if not impossible.
Do remember a specific request for a procedure/treatment from a patient is usually specific to a particular circumstance. Ex. The patient's wish for the use of a respirator if there is a good chance s/he will recover.	Do not ask a patient if s/he wants everything. Everything means different things for different people !If a patient expresses that s/he want everything, explore what that means to the patient using open ended questions and different scenarios
Do use open ended questions to ascertain what the patient is feeling and why.	Don't respond to a patient's statement like "This is so upsetting" with a statement like "I understand". Instead use an open ended question like "Tell me, what is most upsetting about the situation?"
Do use empathic responses only when you have ascertained what the patient is feeling and why.	Don't answer questions you don't know the answer to. Listen and tell the patient that you will try to find an answer for her/him. If you can't find the answer, be honest and let the patient know.
Do remember that open-ended questions and empathic responses require a lot of energy. Open ended questions require significant effort as you listen to the patient's response and empathic responses requires significant concentration as you frame what you are going to say.	Don't block the patient's feelings with premature reassurance. Don't make judgmental statements about the patient. Don't take the patient's anger personally. Don't forget that the patient has the right to accept or reject any or all of your suggestions related to her/his care
Do remember that during EOLDM conversations the patient is processing and responding to the information and conversation on three levels: What is happening to me? How so I feel about this? Now that I've been told, what does this mean for me?	Don't rush through the conversation Don't forget to allow for silences as the patient processes the information s/he has received. Your silence allows time for the patient to react in any way s/he chooses. Sometimes there isn't anything more to say, and silence is ok Don't forget to let the patient know that no matter what happens you will not abandon her/him.

## **Conclusion**

Communication is difficult, especially when conveying bad news. It takes practice and patience. Regardless of how skilled a practitioner may be, broaching the topic of end of life treatment and care with their families is emotionally demanding. Health care practitioners often endure significant stress when faced with this task. And it is essential that they receive support not only from their peers but also from their facility's administrators.

Some of the ways support can be provided is through additional training, and a facility culture that provides opportunities for health care practitioners to express their feelings about mortality as well as end of life and bioethical issues. Similarly, a facility process that encourages health care practitioners to engage in discussions with their peers about the care needs of their dying patients, and routinely acknowledges the complex communication tasks that health care practitioners often have to perform can be of assistance.

I hope that you find the guide to be helpful, and are able to use some of the strategies and examples in your practice. The examples and strategies provided are a brief overview and compilation of approximately twenty years of best practices that were developed mainly by health care practitioners with expertise in patient/health care practitioner communication. The appendices that follow include scenarios that can be employed to practice the guide's communication strategies. The survey that follows the scenarios is related to attitudes, beliefs, training and support in end of life communication and care. It can be used as a pre/posttest training instrument. For

additional information on patient/health care practitioner communication a  
reference list is attached.

## Appendix A

The following scenarios are for you to use in the application of one or more of the communication strategies outlined in the guide

### Scenario 1

A 44 year old surgeon who is married with three children ages 15, 10, and 8 is sitting in your waiting room for a post -op follow up for the removal of a 7 cm mass from his upper left groin. You have just received the pathology report and subsequent review from the consulting oncologist, which determined that the mass is a metastatic rhabdomyosarcoma, an unusual malignant neoplasm in an adult. Your job is to break the bad news to the surgeon.

### Scenario 2

A 31-year-old woman, diagnosed with Hodgkin's lymphoma three years ago recently received a bone marrow transplant. She is in the waiting room with her husband of one year, where they are waiting for the recent results of the treatment. The news is not good. Your job is to let them know that the bone marrow transplant hasn't worked and to provide available options.

### Scenario 3

A 75 year old woman was admitted one week ago through the E.D. with pneumonia, a casted broken arm, and an O2 sat of 84%. Within 24 hours of admission she was placed on a mechanical ventilator and admitted to the MICU. Since her admission she has developed a systemic infection, renal failure, a rash like yeast infection on her torso, and stage two pressure sores on both heels. She has received dialysis for the past three days with no change. The combination of antibiotics has seemed to make little difference in her status. Your job is to let her family know her status and with the family's input develop an appropriate care plan.

## APPENDIX B

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Health care practitioner: Communication and End of Life Decision Making

Your participation in taking the survey and making any suggestions on the survey content is greatly appreciated. The survey is comprised of forty-one questions.

Demographic/Practice Characteristics

Question 1 - Choice - One Answer (Drop Down)

What is your gender?

- Male
- Female

Question 2 - Choice - One Answer (Drop Down)

What is your current job classification?

- Doctor of Osteopathy
- Medical Doctor
- Advanced Practice Registered Nurse
- Registered Nurse
- Resident Medical Doctor
- Resident Doctor of Osteopathy
- Student
- Other

Question 3 - Open Ended - One Line

What is your age?

Question 4 - Open Ended - One Line

What is your title?

Question 5 - Choice - One Answer (Drop Down)

How many years have you been in practice?

- Not Applicable
- 0-2 years
- 3-6 years
- 7-10 years
- 11-14 years
- 15 years or more

Question 6 - Open Ended - One Line

What is your primary area of practice?

Question 7 - Open Ended - One Line

In what setting do you practice?

**Formal Education and Experience in End of Life Care**

Question 8 - Choice - Multiple Answers(Bullets)

During your basic nursing or medical education did you receive any formal training related to patient communication?

- Not Applicable
- No
- Yes (if yes, type of training)
- University/College Course
- Workshop
- Seminar
- Conference
- Web- Based Continuing Education
- Other, please specify

Question 9 - Choice - Multiple Answers(Bullets)

During your basic nursing or medical education did you receive any formal training related to patient end of life decision making?

- Not Applicable
- No
- Yes (if yes, type of training)
- University/College Course
- Workshop
- Seminar
- Conference
- Web- Based Continuing Education
- Other, please specify

Question 10 - Choice - Multiple Answers (Bullets)

During your basic nursing or medical education did you receive any formal training related to hospice, palliative, or end of life care?

- Not Applicable
- No
- Yes (if yes, type of training)
- University/College Course

- Workshop
- Seminar
- Conference
- Web- Based Continuing Education
- Other, please specify

Question 11 - Yes or No

In your practice do you care for terminally ill patients?

- Yes
- No

Page 1 - Question 12 - Yes or No

I am familiar with the SPIKES protocol that is used to communicate bad news to patients.

- Yes
- No

Question 13 - Yes or No

I am familiar with the " American Family Health care practitioner Guidelines for Patient Centered Communication Related to End of Life Care"

- Yes
- No

Question 14 - Yes or No

I am familiar with other protocols/guidelines used to communicate bad news to patients.

- Yes
- No
- If yes, please list

**COMMUNICATION-Following are a series of statements related to communication skills. On a scale of 1-5, with (1) indicating of no importance and (5) indicating of extreme importance , please indicate the importance of each skill to being a good health care practitioner. If the statement does not apply, please click on (6).**

Page 1 - Question 15 - Rating Scale - One Answer (Horizontal)

Educating patient/family about the patient's diagnosis and treatment.

1

2

3

4

5

Question 16 - Rating Scale - One Answer (Horizontal)

Increasing patient's /family's ability to remember what they have been told about the condition/disease .

1 2 3 4 5

Question 17 - Rating Scale - One Answer (Horizontal)

Preparing patient /family about the course of the condition/disease.

1 2 3 4 5

Question 18 - Rating Scale - One Answer (Horizontal)

Recognizing when the patient /family member is anxious/depressed.

1 2 3 4 5

Question 19 - Rating Scale - One Answer (Horizontal)

Encouraging patient /family member to express her/his anxieties about the condition/disease.

1 2 3 4 5

**Question 20 - Rating Scale - One Answer (Horizontal)**

Listening for patient's expressed anxiety about her/his condition/disease.

1 2 3 4 5

Question 21 - Rating Scale - One Answer (Horizontal)

Communicating with a hostile patient or family member.

1 2 3 4 5

Question 22 - Rating Scale - One Answer (Horizontal)

Providing support to patient/ family.

1 2 3 4 5

Question 23 - Rating Scale - One Answer (Horizontal)

Communicating bad news to patient/ family about the diagnosis/prognosis with empathy.

1 2 3 4 5

Question 24 - Rating Scale - One Answer (Horizontal)

Checking with the patient/ family to determine if they understand what has been said regarding the prognosis and treatment of the condition/disease.

1 2 3 4 5

Question 25 - Rating Scale - One Answer (Horizontal)

Knowledge and understanding of cultural differences related to death and dying.

1 2 3 4 5

**END OF LIFE DECISION MAKING- Following are a series of statements related to end of life decision making. On a scale of 1-5, with (1) one indicating a strong disagreement and (5) five indicating a strong agreement please indicate your level of agreement with each statement. If the statement does not apply, please click on (6).**

Question 26 - Rating Scale - One Answer (Horizontal)

I am knowledgeable about end of life communication with patients and families.

1 2 3 4 5 6

Question 27 - Rating Scale - One Answer (Horizontal)

A part of providing routine care to patients is discussing advanced directives.

1 2 3 4 5 6

Question 28 - Rating Scale - One Answer (Horizontal)

I am comfortable talking to patients about personal choice and self determination.

1 2 3 4 5 6

Question 29 - Rating Scale - One Answer (Horizontal)

I am comfortable talking with patients/families about the associated complications of life sustaining treatments such as artificial hydration/nutrition, mechanical ventilation, dialysis, and resuscitation.

1 2 3 4 5 6

Question 30 - Rating Scale - One Answer (Horizontal)

I am comfortable with developing end of life treatment and goals with my patients and their **families**.

1 2 3 4 5 6

Question 31 - Rating Scale - One Answer(Horizontal)

I know when to transition my patients from curative to palliative care.

1 2 3 4 5 6

Question 32 - Rating Scale - One Answer (Horizontal)

I am comfortable with referring my patients to hospice services.

1 2 3 4 5 6

Question 33 - Rating Scale - One Answer (Horizontal)

I am supportive of patients who wish to forgo treatments that could extend life.

1 2 3 4 5 6

Question 34 - Rating Scale - One Answer (Horizontal)

I am comfortable talking with patients and families about code status.

1 2 3 4 5 6

Question 35 - Rating Scale - One Answer (Horizontal)

I am comfortable implementing orders to discontinue life-sustaining therapies. status.

1 2 3 4 5 6

**SUPPORT & IMPACT- Following are a series of statements related to practitioner support and feelings. On a scale of 1-5, with (1) one indicating a strong disagreement and (5) indicating a strong agreement , please indicate your level of agreement with each statement. If the statement does not apply, please click on (6).**

Question 36 - Rating Scale - One Answer (Horizontal)

I am comfortable with my feelings associated with patients who are dying.

1 2 3 4 5 6

Question 37 - Rating Scale - One Answer (Horizontal)

I have adequate peer support for dealing with bioethical dilemmas.

1 2 3 4 5 6

Question 38 - Rating Scale - One Answer (Horizontal)

I have good support for dealing with my own feelings about mortality and other end of life issues.

1 2 3 4 5 6

Question 39 - Rating Scale - One Answer (Horizontal)

I am comfortable talking with my peers about the care of dying patients' end of life issues.

1 2 3 4 5 6

Question 40 - Rating Scale - One Answer (Horizontal)

When a patient dies, I have the opportunity to debrief with my colleagues or team members.

1 2 3 4 5 6

Question 41 - Open Ended - Comments Box

Please make any content suggestions:

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**Thank You for your time in completing the survey and making any content suggestions.**

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