

**Educational Modules for the  
Critical Care Communication (C3) Course -  
A Communication Skills Training Program for Intensive Care Fellows**

Written by the C3 investigators  
(Robert Arnold, Judith Nelson, Thomas Prendergast, Lillian Emlet,  
Elizabeth Weinstein, Amber Barnato, and Anthony Back),  
based on modules from Oncotalk (by Anthony Back, Robert Arnold,  
Walter Baile, James Tulskey, and Kelly Fryer-Edwards)

Module 1: Fundamental Communication Skills

Module 2: Giving Bad News

Module 3: Determining Goals of Care for Patients Who are Not Doing Well

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## CRITICAL CARE COMMUNICATION (C3)

### MODULE I:

#### FUNDAMENTAL COMMUNICATION SKILLS

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*These learning modules for intensivists have been developed based on the success of communications skills modules for oncologists, which are available through Oncotalk at <http://depts.washington.edu/oncotalk/learn/modules.html>*

In this module the term ‘family’ is used to refer to all the people who are emotionally intimate or biologically connected to the patient. Thus a patient’s ‘family,’ for our purposes, may include an unmarried partner, a close friend, and/or a second cousin—in addition to a spouse, children, or parents.

#### Learning Objectives

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After reading this section, participants should be able to do the following:

1. List four fundamental principles for better intensivist-family communication.
2. Describe the "Ask-Tell-Ask" principle.
3. Describe the "Tell me more" principle.
4. Describe the "Respond to emotion" principle and the mnemonic NURSE.
5. Describe the differences between "monitors" and "blunters," and identify techniques to best address their information needs.

#### Why This Course?

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Communication between physicians and patients and their families is “consistently identified as the most important and least accomplished factor in quality of care” in the intensive care unit (ICU). Each year, over half a million people in the United States die in an ICU or following treatment in an ICU during their final hospital admission. ICU patients are able to participate in their own end-of-life discussions less than 5% of the time, and they frequently have no advance directives available. Thus, intensivists turn to surrogates. Family members are conventionally recognized as surrogate decision-makers because they are presumed to know the patient’s preferences and to act in the patient’s best interests. Intensivists, not only need to inform the patient and/or family members about the diagnosis, prognosis, and treatment, but also, in most

cases, must help the family to make decisions that reflect the patient's goals while at the same time attending to the family's emotional needs at a time of severe stress.

Multiple studies suggest that communication with family members in the ICU is inadequate. One study reported that half of family members, 48 hours after admission, did not understand even basic information about the patient's diagnosis, prognosis, or treatment. Malacrida et al. (*See Readings and Resources List.*) interviewed 123 relatives of patients who died in the ICU, 17% of whom said that they received insufficient or unclear information on their loved one's diagnosis. During the ICU stay, anxiety and depression among family members was magnified when they felt excluded from decision making. Curtis et al. (*See Readings and Resources List.*) found that in family meetings, physicians spoke over two-thirds of the time, and that in 29% of the meetings, physicians missed opportunities to listen, acknowledge, and address families' emotions; explore patient preferences; explain surrogate decision making; and affirm families' concerns of non-abandonment. Abbott et al. (*See Readings and Resources List.*) investigated sources of conflict with family members of patients who died in the ICU. About half of the families reported conflicts with medical staff, usually involving poor communication. Finally, post-traumatic, stress-related symptoms in family members 90 days after their loved one's discharge or death were more common among those who thought that information they received was incomplete, who shared in decision-making, and whose family member died in the ICU.

Clinicians also report dissatisfaction with family communication. For example, over 70% of clinicians report perceived conflicts with other staff or family, typically surrounding decision-making for patients at high risk of dying. These conflicts were often severe and were significantly associated with job strain. Many intensivists will say that communication with families is the most stressful part of their job. Worries about "futility" and feeling overwhelmed by "demanding" families, may be part of the reason that one third of physicians and one half of nurses report being burned out.

The common element among these deficiencies is poor communication skills. A recent survey of pulmonary and critical care fellows documents scant formal teaching on communication about death and dying, a lack of explicit feedback about basic communication skills, and an absence of

role models with such expertise. A separate survey of physician and nurse directors of 600 ICUs across the United States identified inadequate training and the absence of clinician-experts in communication as a major barrier to better end-of-life care for patients dying in ICUs. Physicians report lacking the skills needed to communicate complex medical information or to address families' emotional needs.

Although physicians frequently regard the ability to communicate as an inborn talent, physicians can learn these skills if evidence-based methods are used. A variety of studies of internists and family medicine physicians show that communication skills training leads to more discussion of psychosocial issues with decreased patient distress, more inquiry about patients' views, greater physician ability to elicit patient values and feelings, and greater confidence in communicating bad news. Finally, a Cochrane systematic review of communication skills training for health care professionals working with cancer patients and their families concludes that: (1) it is clear that communication skills do not reliably improve with experience alone, and (2) training programs using appropriate educational techniques are effective in improving skills. However, fewer data exist regarding the impact of these improved communication skills on patient or family outcomes.

### **Fundamental skills that will help**

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In teaching clinicians to improve their communication skills, we have found five fundamental principles that help physicians deal with many clinical situations. These principles summarize a great deal of the communication literature written by empirical researchers and master clinicians. These are not, of course, the only principles around, and other respected experts use teaching aids that are somewhat different. However, we, as the clinicians who developed this training, use these principles frequently ourselves and consider them “road-tested.”

Note that the principles emphasize what physicians should actively do in trying to communicate better—not what physicians should avoid doing. When improving any skill, it is easier to try to do something rather than to try not to do something. So even though this learning guide includes barriers and pitfalls, we recommend that you focus on the principles. A series of principles for action is likely to be more useful to take away from this training than a list of barriers.

Communication between patients and/or family members and intensivists is the bedrock of the therapeutic relationship, and a physician's working model for how this relationship should function frames all of his/her efforts at communication. While much of the communication literature aimed at other specialties addresses interactions between a doctor and patient, much of the communication in the ICU occurs with a family member. Regardless of whether the communication occurs with the patient or the family member, the fundamental principles remain the same. Therefore, the rest of this module will talk about "intensivist-family communication" simply because this is the most common situation. *Note: in this module, the term "family" is used broadly to mean both biological relatives and friends who are at the patient's bedside in the ICU.*

Four models of surrogate-physician communication have been empirically validated. A common model for an intensivist-patient relationship is the *directive model*, in which the intensivist (the expert) take responsibility for what should be done to the patient and dispenses it to the family as required. At the other end of the spectrum are consumer theories, in which the family "buys" what s/he requires from the intensivist. In the *informative model*, for example, the physician provides information but does not discuss the patient's values with the family. However, the theory that underlies our curriculum recognizes that medicine and the patient-physician relationship is essentially a moral enterprise that is grounded in trust. This view of communication fosters shared decision-making in which the intensivist brings his/her expertise about critical care to bear on a patient's and family's goals, concerns, and ideas about well-being. The two models that fit within this view are called *facilitative* and *collaborative*. In both of these models, the physician elicits and helps clarify the patient's values with the family. The difference is that in the collaborative model the doctor is involved in the decision-making process and provides a recommendation. Interestingly, in the empirical study in which these were developed models were developed, doctors never asked families which model they preferred.

## Five Fundamental Principles for Better Communication

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### *Principle 1: A Central Skill "Ask-Tell-Ask."*

A great deal of communication in the ICU involves providing information, but this does not mean that communication should be one way. For any important communication:

**Ask** the family to describe their current understanding of the issue. This will help you craft your message to take into account the patient and family's level of knowledge, emotional state, and degree of education. It allows you to determine if the family has misperceptions (*They said you could do a transplant*) that you can address when you give information (*I know they mentioned a transplant. I wish that was an option. His infection however means that a transplant is not possible*). It gives you information about their medical knowledge and language style. "Ask" also gives you the opportunity to determine the family's concerns and then negotiate the agenda for the conversation. The following are some sample questions to open your conversation:

- *"What is the most important issue for us to talk about today?"*
- *"To make sure we are on the same page, can you tell me how you see the situation?"*
- *"What have the other doctors been telling you about your loved one's illness since the last time we spoke?"*

**Asking permission** prior to giving information also serves to help build a relationship. It shows respect for them and allows them to have some control over the conversation. Second, it allows you to check to make sure that everyone is present who needs to hear the information. Finally, asking permission lets the family know that they need to focus on you as you are going to give information. Ways to do this include:

- *"Is this a good time for me to talk about what has happened since your dad was admitted?"*
- *"Would you like to hear our recommendation about what should be done?"*

After you have done this, the next step is to...

**Tell** the family in straightforward language what you need to communicate—the bad news, or treatment options, or other information. Given that the family is stressed and overwhelmed it is best to think about the 2-3 take home messages you want them to get and focus on that. Too much information can be confusing. Information should be provided in short, digestible chunks. A rule of thumb is not to give more than three pieces of information at a time. Then check in to make sure they understand what you have said (*what questions do you have about that*) before you proceed. Use eighth-grade English in communicating. Avoid medical-ese. Before you go on, you should...

**Ask** the family whether they understand what you just said. This gives you the opportunity to check their understanding. Did they get the facts straight? Is their understanding appropriate? Did they hear what was said? Consider asking the family to restate what was said in their own words. This will give them a chance to ask questions, and that will tell you where to go next—what details to elaborate, what implications to discuss, what things to repeat. For example, you could say *"Who are you going to tell about this visit when you get home?"* or *"To make sure I did a good job of explaining to you, can you tell me what you are going to say?"* Or in the next meeting, you could start out with *"I am not sure I was clear during our last meeting when I explained the problems to you. To help me out, can you tell me what you remember I told you about your disease?"*

***Principle 2: When You Are Stuck, Ask for More Information: "Tell Me More."***

If you find that the conversation is going off track, it is helpful to note that in your own mind, and you may even want to mention it to the patient by saying, *"I think we're not on the same page."* To get back on track, it is usually helpful to invite the family to explain where they are in the conversation and to remember that every conversation really has at least three levels:

1. The first level of conversation could be called the *"What is happening?"* conversation, in which the family is trying to apprehend and understand information.
2. The second level of conversation has to do with emotions—at this deeper level, patients or family members are asking themselves *"How do I feel about this?"* In addition to

trying to figure out their emotions, they are also assessing whether these emotions are valid, and whether they can express them to the intensivist.

3. The third level of conversation is an identity conversation, involving what the new information means in terms of the patient or family member's sense of self—addressing the question *"What does this mean to me?"*

Knowing that these three different conversations are taking place can enlarge a physician's sense of where the *"tell me more"* request can lead. Some examples of useful invitations to *"tell me more"* include the following:

- *"Could you tell me more about what information you need at this point?"*
- *"Could you say something about how you are feeling about what we've discussed?"*
- *"Could you tell me what this means for you and your life?"*

***Principle 3: Use reflections rather than questions to learn more<sup>1</sup>***

Reflections are restatements of the family's words or guesses at what the family means.

Reflections can be simple or complex. *Simple* reflections paraphrase what the person said and do not add meaning or interpretation. They do not have to be verbatim but often are. For example:

SON: I know he is really sick but I can not give up hope.

MD: You can not give up hope.

SON: I have to be hopeful. I am not sure what I will do if he gets sicker or does not make it.

*Complex* reflections, on the other hand, go beyond what person says and includes the clinicians' thoughts about speaker's underlying emotions, values, or beliefs. These reflections are riskier because clinicians can be incorrect in their interpretation; however, they also are more powerful as they may help the speaker see things differently. For example:

Daughter: I just don't know how I'm going to tell my kids about this. They will be devastated.

MD: I can see that you care deeply for your kids and do want them prepared for what is happening to their grandmother

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<sup>1</sup> From Pollak K, Childers JW, Arnold RM. Applying motivational interviewing techniques to palliative care communication



Daughter: Yes, I do love them and want them to be ok. I just am not sure if I should have them come in to see her or if it is better for them to stay at home.

Reflective statements serve three functions. First, they can convey empathy (see below). By reflecting, clinicians let surrogates know both that they are heard and that the doctor is trying to understand their perspective. Second, reflective statements empower the family to take control of the conversational platform. The typical clinical encounter involves clinicians asking a question, the family answering, followed by further questions from clinicians. This format reflects clinicians' agendas rather than the family members and can inhibit them from telling their stories. Reflections, however, allow the family member to steer the conversation.

Many questions can simply be changed into a reflection by re-ordering the words or changing the vocal inflection at the end. For instance, the question "So you're not sure you want to have a feeding tube?" can be transformed into a reflection by saying, "So you're not sure you want to have a feeding tube." The question requires an answer that typically will be a "yes" or "no". More importantly, the clinician is expected to direct the conversation further. When the clinician reflects instead, however, and allows silence and time for the family member to respond, they can explore the complexity of his decision-making, perhaps including more information about what artificial nutrition means to him, family experiences with feeding tubes, and hopes for survival.

***Principle 4: Skills for Responding to Emotion.***

Being in the ICU, typically involves bad news. There is often the potential for death. In addition, there may be a loss of physical function (for example, a stroke, surgery or just being in the hospital) social function (being able to be a breadwinner) or quality of life (the physical or psychological pain associated with being or watching a loved one suffer). When faced with loss, people react by emoting.

Strong emotions – disbelief, sadness, anger, frustration and hopelessness – are thus normal in the ICU. Often the questions that people ask after hearing bad news have both a cognitive and affective component (e.g., “*Why did this happen?*” may be a question about why Dad’s lungs got worse or/and be an emotional statement of disbelief.) If you recognize the common emotional reaction to bad news, you are more likely to respond with empathy.

It is important to attend to these emotional reactions. First, when people are experiencing strong emotions they are less able to hear cognitive information. This means that responding to bad news with cognitive information is not very effective because the information is almost never heard. Second, in the midst of a strong emotional reaction, people find it hard to make decisions. In fact, most psychologists counsel people to NOT make big decisions in the midst of strong emotions. Thus, recognizing that the family is having an emotional reaction will help you from pushing forward with decision-making. The family needs time to grieve and express their emotions. After doing this it is typically easier for the family member(s) to attend to what comes next. Third, what most people want when expressing strong emotions is to feel that their situation and emotions are heard and appreciated. This is the definition of being empathic – being able to recognize and then show that you are trying to recognize what the other person is going through. Being empathic is associated with family satisfaction and trust. Fourth, acting empathically can enable patients to connect their emotional reactions to their own important values. Empathy helps people talk more about what they are feeling. In this conversation they can begin to name the stories that are tied to their emotions (*I am feeling guilty because I pushed my dad to have the surgery. And that is interfering with my thinking about what my dad really wanted*). This may help family member think more deeply about the values at stake and reflect on what their loved one really wants. Conversely, encouraging this conversation helps the

physician learn more about the family and patient's story. Finally, and most practically, acting empathically can enable physicians to create medical plans that serve patients better. By understanding the patient's story and values better, the doctor can suggest a plan that best promotes the patient values.

Understanding the family's perspective will result in the doctor discovering more about the thoughts and feelings they are experiencing. Having discovered all this, how should the intensivist respond?

The concept of an "accepting response" is helpful here. Rather than providing immediate reassurance, rebuttal, or agreement, the accepting response does the following:

- accepts what the family says non-judgmentally,
- acknowledges that family members ought to hold their own views and feelings, and
- validates the importance of the family's contributions in a therapeutic relationship.

It is important to note that acceptance is not the same as agreement. A physician could accept that a patient wishes to be cured of cancer, yet not agree that it is possible. This distinction is important in building and maintaining a relationship.

**A helpful mnemonic** summarizes what to do in responding and accepting patient emotions: **NURSE**.

**N = NAMING:** You can begin by naming an emotion for yourself, as a way of noting what is happening in the encounter, and you may even want to name the emotion in talking with the patient or family as a way of showing that you are attuned to what they are experiencing. (*"It sounds like you are worried that your mother would not have wanted this treatment."*) Naming, restating, and summarizing are all ways to begin accepting and responding to family emotions. This may require that physicians read non-verbal clues that family members display. It is important that when using "naming," the physician is suggestive, not declarative; *"I wonder if you're feeling angry,"* or *"Some people in this situation would be angry,"* rather than *"I can see you're angry about this."* People don't like being told what they are feeling.

**U = UNDERSTANDING:** A sensitive appreciation of the family's predicament or feelings is an important prerequisite for responding in a way that builds the relationship. Particularly important is to avoid giving premature reassurance at this point, even though the temptation to do this is strong. It is better to make sure that you have a clear understanding, and this may require some exploration, active listening, and use of silence. *"I think I understand you as saying that you are concerned about the effect on your kids of seeing [the patient] like this in the ICU,"* can be an effective way to validate patient emotions. Paradoxically, saying *"I cannot imagine what it is like to (X)"* is a good way to show you understand.

**R = RESPECTING:** This can be a non-verbal response, involving facial expression, touch, or change in posture, but a verbal response is helpful because it can be more explicit in giving patients and families the message that their emotions are not only allowable but important. Acknowledging and respecting a family's emotions is an important step in showing empathy. In terms of how much to do on this step, consider matching the intensity of your acknowledgment to the family's expression of emotion—a strong emotion deserves a strong acknowledgment.

Praising the person's coping skills is a good way to show respect. *"I am very impressed with how well you've cared for your mother during this long illness."* or *"You are asking a lot of very good questions."*

**S = SUPPORTING:** Several types of supporting statements are possible. Physicians can express concern, articulate their understanding of a patient's situation, express willingness to help, make statements about partnership, and most importantly, acknowledge the family's efforts to cope. *"I can see that I have given you an awful lot of news. I want you to know that I am going to be around all day today if you have questions. And I will be back tomorrow to talk to you more. We will touch base with you on a regular basis to make sure you are clear about what is going on"*.

**E = EXPLORING:** Letting the family member talk about what they are going through often helps them feel heard. Thus, it can be therapeutic to explore their story (*"What has this been like for you?"*) In addition, sometimes you may not be sure what the family member is thinking or feeling. In these situations, it can be useful to explore by asking (*"This is a lot to hear. What are you thinking?"*). Another way to do this is to ask about their concerns or questions. The point is to try to get the family member to talk about their experience.

The most effective empathic statements link the "I" of the doctor to the "You" of the family: *"I sense how upset you are feeling about the results of the CT scan."* It is not necessary to have had the experience to empathize; but it is necessary to put yourself in the patient's and/or family's position and to communicate that understanding back to the patient. Also, empathy should not be confused with sympathy, which is a feeling of pity or concern from outside the patient's position.

***Principle 5: Assess the Other Person's Informational, Decision-making and Coping Style.***

People are different. Some people want a lot of information, others not as much. A recent study found that while some family members want to hear the doctor's recommendations about what to do, others specifically said that they did not feel it was the doctor's role to give

recommendations. Unfortunately, there are no demographic factors that can help a physician determine what a family member wants. What is a physician to do?

First, understand that psychologists have identified two main coping styles: “monitors” and “blunters.” People who use problem-focused coping have been termed “monitors.” They typically seek information to help them manage. Monitors are very interested in planning ahead, and are highly problem-focused. In particular, monitors may find that, as their loved one’s condition worsens beyond the possibility of recovery, they hit a wall in seeking information. With these patients and family members, it may be helpful to limit or contain their information seeking and gently shift them towards acknowledging their emotions (NURSE).

People who use emotion-focused coping are termed “blunters.” They tend to cope by avoiding information, distancing themselves, and engaging in denial of their situation. Blunters often avoid practical planning, which, in a patient, almost ensures that others will be making decisions for them at the end of their lives. It may be necessary to contain their emotions and shift them towards information and practical planning using “**ask-tell-ask.**” Although these patients are said to be emotion-focused, they may not be ready to go beyond denial with you until they have developed a very high level of trust. It may be counterproductive to give large amounts of information in the early stages of your relationship with a blunter.

A caveat: These are general styles – most people are some combination of blunting and monitoring. And what people might want/need can change over the course of their loved one’s illness.

People often fall back on routines, as they try to cope with loss. It is therefore important to learn about other losses the family has dealt with and how they have coped with these losses. (“*Have you had anything like this happen before?*”) Asking about how the family gets along or how they make decisions may help you understand the family dynamics. Asking explicitly about how people cope can be useful. (“*How are you getting through this?*” or “*How are you coping with this?*”)

In addition, if you are unsure you can always *ask* the family what would be most useful to them (*Some people like to hear about all the medical details. For other people, lots of medical information is overwhelming and it is better to hear the “big” picture. Which kind of person are you?*). Similarly, prior to giving information, ask permission (“*Would it be useful if I gave my view?*”)

Finally, and most important, the fact that people differs means that you need to change your communication style based on the family. The best you can do is try something – either cognitive information or empathy and see the impact on the family. You have to be able to watch to see the impact of your words on the family and respond appropriately.

### **Pitfalls/Common Barriers to Good Communication**

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- 1. *Giving pathophysiology lectures:*** Don’t get caught up in potentially confusing medical details. The key is to begin with the “big picture,” and then if the family has questions, you can go into more detail.
- 2. *Ignoring the context of the communication encounter:*** Don’t force your agenda. If the family is too emotional about the bad news, give them time to grieve before moving on. If they are having trouble deciding what their loved one would want, give them space. If they are hesitant in talking about the issues, give them time during the conversation when there is silence so that they can think.
- 3. *Not finding out the family’s information needs and styles:*** Asking for family members’ information needs allows them some control over the situation. In addition, occasionally, people are emotionally unprepared to hear certain information and will tell you that before you start.
- 4. *Launching into your agenda first without negotiating the focus of the interview:*** Be clear that you know what BOTH you and the family want to discuss. If you start off with your views and their views are different, chaos typically results.
- 5. *Offering reassurance prematurely:*** Resist the temptation to make things better, for example rushing to suggest that things may get better. This desire to make things better is very

common among health care providers, but families report that it does not make them feel better. If there are treatment options, you can give them after delivering the news and allowing the family to process it. Reassuring too quickly leads the family to believe that you do not understand what they are going through.

- 6. *Pushing the family to make a decision, before they have had a chance to grieve the loss:***  
Remember that when people are emotional, they may not be thinking clearly. Thus pushing people to make decisions before they have time to grieve may be counterproductive. The family member will feel like you do not appreciate what they are going through and that you are only trying to “move their loved one through the system.” Attend to the family member’s emotion first. If you are unsure, ask if they are ready to talk about some treatment decisions. (*“I wonder if you would be okay with us talking about what comes next.”*)
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## CRITICAL CARE COMMUNICATION (C3)

### MODULE II: GIVING BAD NEWS

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*These learning modules for intensivists have been developed based on the success of communications skills modules for oncologists, which are available through Oncotalk at <http://depts.washington.edu/oncotalk/learn/modules.html>*

In this module the term ‘family’ is used to refer to all the people who are emotionally intimate or biologically connected to the patient. Thus a patient’s ‘family,’ for our purposes, may include an unmarried partner, a close friend, and/or a second cousin—in addition to a spouse, children, or parents.

#### Learning Objectives

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After reading this module, participants should be able to do the following:

1. Define bad news and what makes it bad.
2. Identify barriers to giving bad news to patients and family.
3. List and explain the six steps for giving bad news.

#### Why is This Topic Important?

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Bad news can be defined as any information which adversely alters one’s expectations for the future. Intensivists give bad news thousands of times during the course of a career. Indeed, being admitted to the intensive care unit (ICU) can be considered bad news in and of itself. Given the high morbidity and mortality associated with admission to the ICU, giving bad news is a core skill for most intensivists.

Despite the importance of these skills, few clinicians have been trained to give bad news. It is therefore no surprise that intensivists find that giving bad news is stressful and/or that their skills need improvement. Families also often complain that the doctors give bad news bluntly or in a detached manner, create false hopes through excessive optimism, or focus on detailed medical or statistical information without offering an interpretation of what the information means in lay terms and for this patient. However, when bad news is communicated well, it can have an important impact on outcomes such as family satisfaction and decreased anxiety and depression.

Most studies about “breaking bad news” focus on the physician or patient experience. Although we assume the principles are the same, few focus upon family and surrogate decision makers, the people to whom intensivists most often communicate bad news. Throughout this module, we refer to the family rather than the patient and/or family because intensivists most frequently communicate with family and surrogate decision makers.

## **Recommended Procedure**

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As with any medical procedure, giving bad news requires a coherent strategy in order for it to be accomplished successfully. In this case the strategy encompasses a series of six distinct communication steps, summarized with the mnemonic **SPIKES**.

**S = SETUP:** Set up the situation so it has a good chance of going smoothly. First, make sure you have the medical facts straight. Be clear that the team is in agreement about these facts and their meaning. Second, assess your emotional state. Is it going to be hard to give bad news to this family? If so, it might go better if you have someone to talk to ahead of time about these issues. Third, it may help if you are clear about what your goals are for the conversation. What are the key concepts you want to get across? Fourth, given you may be meeting with a variety of people, the discussions might go better if you have a nurse or social worker accompany you. Fifth, make sure all the people you want to talk to are at the meeting. It can be frustrating to talk to a family and an hour later have another group of people show up and want you to go over the same information again.

Other things to do before the meeting to help you focus on the family include the following: (1) Turn your pager off or give it to someone else so you are not interrupted. (2) Sit down, make eye contact, and get reasonably close to the family members. (3) Introduce yourself to all the participants and make sure you know who they are. Finally, anticipate that family members will be upset and have some tissues ready.

**P = PERCEPTION:** After setting the meeting’s agenda, find out the family’s perception of the medical situation. (This is the ask in Ask-Tell-Ask) What have they been told about the situation? (*While I read the chart and spoke to the other doctors, it is helpful to hear what the doctors have told you is going on with your son*) It may also be useful to hear what they have

been told about the patient's prior medical situation? (*What have his outpatient doctors said is going on with his cancer?*) What have they intuited about the situation? Often what families are told and what they believe are two different things. Because of people's optimistic bias for example ("Dad is a fighter and so will do better than most"), families can both hear what the doctors say and still believe that the outcome will be better than what is predicted. Thus it is useful to both ask: "*What have the doctors told you?*" and "*What do you think is happening?*". The latter gets at their expectations/hopes for intensive care. Note any strong denial or its mimics (e.g., avoidance of topics or excessive optimism). Understanding what the family members know allows you to be prepared for how difficult the news is likely to be for them. Also if you know what they do and do not know you can more successfully build on their knowledge base.

**I = INVITATION:** First, find out how much information the family wants. ("*Are you the kind of person who is interested in knowing all of the details or just a general overview? Some people want to know everything about what's going on, and others really would rather not hear all of the details. What kind of person are you?*"). Keep in mind that different family members may have different preferences here, and also the scope of the information they need may differ. For example, certain family members may need or want to know the likely duration and extent of the acute illness and future caregiving burden to make decisions related to work and family obligations. (If the preferences differ, you can negotiate this prior to giving news). Families may have seemingly inconsistent or conflicted preferences—both wanting to know and not know at the same time. This may be a reflection of both wanting to know what to expect, but also not wanting to give up hope. One can address both needs simultaneously with the "hope for the best but prepare for the worst" approach to communication. (*See Module VII, page 8 for more about this*).

Second, before you give information, invite them to tell you what they are willing to hear. ("*Would it be okay, if I tell you everything I know?*") It may also be helpful to ask if everyone who needs to be there is there as it will keep you from having to give the same information multiple times. Asking them to tell you about their needs for information allows them some control over the situation. In addition, occasionally, people are emotionally unprepared to hear news and will tell you that before you start.

**K = KNOWLEDGE:** First, fire a ‘warning shot,’ so that the family members can become emotionally prepared for the bad news. This can be done a variety of ways: asking if they want a chaplain to be at the meeting or asking if there are any family from out of town who should be there clearly suggest that the information is serious. Alternatively, one can in the introduction to the meeting, make it clear that things are not going well. (*Unfortunately, things have not gone as well as we would like*).

Second, when giving bad news it is important not to use jargon or vague language. Use language that matches the patient and/or family members’ level of education. One technique is to imagine that you are explaining the situation to your child’s eighth grade class.

Third, don’t get caught up in the medical details. The key is to give the ‘big picture,’ and then if the family has questions, you can go into more detail. That means thinking – before the meeting – about the three big picture conclusions you want them to take away from the meeting.

Fourth, it may be helpful to *chunk and check* when giving information. Give a piece of information and check in (*Does that make sense?*) Then give another piece of information.

Fourth, if their perception (from “P” above) was inaccurate, you can refer to the information and correct it at this point. An example would be (*“Now, you remember that your dad’s heart stopped, and he received CPR for 20 minutes before the paramedics gave him the shock that brought his heart rhythm back. That whole time his brain was getting very little oxygen. The brain test we did today showed that his brain was severely damaged. The only part that is working is the part that controls blood pressure and breathing, the brainstem; the parts of the brain that allow him to be conscious and to think and interact don’t work anymore.”*)

After giving this news, stay quiet for at least 15–30 seconds to give the family time to absorb the information and respond. Most of the time, people initially respond to bad news with emotion. (*See Module I.*)

**E = EMPATHIZE:**

Use empathic statements to respond to family members' grief over the losses or possible losses associated with the news. (*See Module 1.*) This allows them to see that you understand what they are going through and that they have an advocate on their side. Interestingly, data suggests that 'just listening' and attending to emotions, decreases their negative impact and increases their ability to hear the material. If someone begins to cry, wait until they are ready to talk; then remember NURSE, (*See Module 1.*), and use an empathic response such as "*This must be a shock to hear.*"

Resist the temptation to fix things, for example rushing to suggest that things may get better. This desire to make things better is very common among health care providers, but families report that it does not make them feel better. (If there are treatment options, you can give them later. Reassuring too quickly leads to family to believe that you do not understand what they are going through.)

Another effective way to show that you are trying to understand what they are going through is to allow them to ask questions about what you have said. ("*What questions do you have about what I said?*" "*Tell me, are there aspects of this information are causing you concern.*") It is important to keep asking (*What other questions do you have?*) until the family makes it clear they do not have more questions because often the important questions are not asked initially but only after they have developed some trust in you.

**S = SUMMARIZE AND STRATEGIZE:** Prior to talking about the next steps, ask the family if it is alright for you talk about what the plan and next steps are ("*Would it be okay, if I tell you a little about what the next steps are?*") In addition to giving the family some control of the situation, this question allows you to check in to make sure the family is psychologically ready to talk about the plan. (If the family responds to this with emotions or hesitation, go back to EMPATHY).

Next, present what you are going to do (the plan). While families appreciate empathy, they also want to know how you are going to help them deal with the situation. They want your guidance and recommendations. This may involve a treatment recommendation, a therapeutic trial, further

testing or a discussion of treatment options. (*See Module III.*) Be as concrete as possible, and check on the patient and/or family's understanding after every piece of information. (*"Does this make sense to you?"* or *"Are you clear about the next steps?"*)

In addition to presenting the plan, it is often helpful to let the family know what you are watching for. Again, the point is that bad news can make the future uncertain, and you are trying to make things as predictable as possible. This helps them gain some control over their uncertain future. Telling them how to contact you if they have questions and when you plan on meeting next may also help.

### **Pearls /Ideas to Facilitate Giving Bad News**

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1. ***Eliciting the patient and/or family's concerns*** can help them feel heard and help you address their primary worries. (*"What concerns you most about this news?"*) These concerns may range far beyond the medical decisions at hand and may represent important concerns and barriers to treatment, e.g., *"How much time will I have to take off work to care for him?"*
2. When patients and/or family members ask difficult questions such as *"Is there any chance he will ever wake up?"* two things may help. First, one can ***attend to the emotions underlying the questions*** (*"I can see how much you want this to happen."* Or *"I wish I could answer that question right now. I know it must be hard not knowing."*) Asking about their effect first will give you a sense of why they are asking the question. ***Reassure them that you will provide information about prognosis so they don't think you're being evasive.*** For example, you might say, *"I will answer your question, but first tell me XXX?"*
3. ***Be aware of your own emotions such as sadness, guilt, disappointment, or shame.*** Discuss these with colleagues prior to the meeting to decrease the likelihood they will interfere with your encounter with the patient and/or family.
4. Try to ***accept that being empathic, interested, and affirming are powerful verbal techniques that the patient and/or family recognize as demonstrations of your support.***
5. You can ***help your patient and/or family members "hope for the best while also preparing them for the worst."*** Acknowledging that these two apparently conflicting emotions may

coexist gives you the opportunity to explore hopes, concerns, and signals that you are willing to discuss both.

### **Pitfalls/Common Barriers to Good Communication**

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- 1. *Feeling you are responsible for maintaining the patient's hope:*** Hope is not something that is ours to give or take away. People have their own inner resources. Careless language or lack of attention can in themselves lead to undermining hope, but overall, hopefulness is something that comes from within a patient or family member. Trying to invent ways to create hope can simply lead to awkwardness or dishonesty, and not communicating important information for fear of taking hope away is withholding important information. What is most helpful and hope inducing is attentive listening and active presence. Explore with the family things they may hope for that do not involve patient recovery: comfort, dignity, a peaceful death.
- 2. *Ignoring your own feelings:*** Being aware of your own feelings is important because it helps you to guard against subconsciously protecting yourself from the anxieties of giving bad news. Unacknowledged feelings can become distractions and introduce static into a context where bad news has to be delivered. Make a conscious effort to be aware of your feelings about giving bad news or interacting with a particular family, family member, and/or patient, acknowledge them and set them aside in order to be able to concentrate on the patient and family. (*See Module VII for more about this.*)
- 3. *Making assumptions about what the family knows and doesn't know:*** As mentioned in Module I, multiple studies suggest that communication with family members in the ICU is inadequate. It is not uncommon for family members to not understand basic information about the patient's diagnosis, prognosis, or treatment. If you aren't clear about what family members know and understand you're not only unprepared to successfully build on their knowledge base, but also for how difficult information or news is likely to be for them. In addition, you're losing an opportunity to build a relationship, as beginning by ascertaining both the understanding and information needs of family members shows that you are willing to listen to and negotiate their concerns.
- 4. *Talking too much:*** Curtis et al. (*See Readings and Resources List.*) have extensively looked at doctors' behavior in family meetings. Doctors tend to dominate family meetings by talking

over two-thirds of the time. Nearly one-third of the time they missed opportunities to listen, acknowledge, and address families' emotions; explore patient preferences; explain surrogate decision making; and affirm families' concerns of non-abandonment. These facts underscore the importance of listening.

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## CRITICAL CARE COMMUNICATION (C3)

### MODULE III:

#### DETERMINING GOALS OF CARE FOR PATIENTS WHO ARE NOT DOING WELL

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*These learning modules for intensivists have been developed based on the success of communications skills modules for oncologists, which are available through Oncotalk at <http://depts.washington.edu/oncotalk/learn/modules.html>*

In this module the term ‘family’ is used to refer to all the people who are emotionally intimate or biologically connected to the patient. Thus a patient’s ‘family,’ for our purposes, may include an unmarried partner, a close friend, and/or a second cousin—in addition to a spouse, children, or parents.

#### **Learning Objectives:**

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By the end of this module, participants should be able to do the following:

1. Describe a value-based approach to discussing goals of care with families in the intensive care unit (ICU) when the patient is not doing well.
2. Be able to ask five questions to help surrogates describe their loved one’s values.
3. Describe the relationship between giving bad news, discussing values, and talking about transitioning to focusing only on symptoms in the ICU.

#### **Why Is This Topic Important?**

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One way to describe a patient’s course in the ICU is to see it as a series of “bad news” conversations and transitions to a new health state. For most patients, being admitted to the ICU means that they have become critically ill, and this is bad news. In addition, for many patients being in the ICU has long-term negative implications for either their ability to function or their mortality (e.g., patients who have a stroke or heart attack or worsening of end-stage organ disease). An intensivist meets with the patient/family, discusses this news, and talks about what can be done to improve the patient’s health status to be as close as possible to baseline. The benefits of treatment (e.g., the hope of promoting the patient’s quality or quantity of life) are weighed against the risks and costs, and a treatment plan is initiated. A few days later, the patient may develop a new complication requiring another conversation to communicate bad news and, if the benefits outweigh the costs, another treatment is initiated. Finally, for some patients, at some point, the doctors believe that the current treatments are unlikely to meet the patient’s goals

or that the cost of trying to meet these goals outweighs their benefits. At this time, they approach the family to talk about transitioning to a focus more on patient comfort and less on treatments to reverse medical complications.

A number of considerations make having these conversations in the ICU particularly difficult. First, the intensivist often does not have a pre-existing relationship with either the patient or the family. This means s/he does not know a lot about what is important to them or about what they have previously spoken about with other doctors. It also means that s/he does not understand a lot about the family dynamics or how they respond to stress or make decisions.

Second, transition conversations in a field like oncology can take place over two to three outpatient visits during which the patient can talk to family members and deliberate over which way s/he wants to go. In the ICU, because of medical acuity, there is a perceived need to make decisions on a much more accelerated schedule over hours to days. Surrogates often feel like they are on a roller coaster and do not have the time to emotionally process the rapid changes in their loved one's health status. In addition, because the patient typically is incompetent, the family can not ask the patient what s/he wants or values.

Third, it is often hard for family members to understand why the current treatments cannot achieve their goals. Given the patients often have chronic illnesses; this may not be their first time in the ICU. In the past, they were very sick and still got better (often with the same treatments, they are getting now). In addition, multi-system organ failure is a common reason for death in the ICU and the combination of factors may be difficult for families to understand. Given that individually each factor is theoretically reversible, it is confusing why the combination can not be fixed. Finally when the treatments being withdrawn or forgone are the same treatments that the doctors recommended instituting only a few days ago, it can be confusing to family members.

Fourth, intensivists like to talk about what they are doing to help patients get better and return to their previous level of functioning. Discussing the fact that they cannot make this happen can cause feelings of inadequacy and loss.

Finally, and probably most importantly, the transition in the ICU is often to death over in a very short time period. A decision to shift goals and focus on comfort for a patient on a ventilator and pressors likely means that the patient will die relatively quickly. This both raises the stakes of the loss and makes it harder for the family to think of other things to hope for, exacerbating their sense of loss and guilt and increasing the emotional cost of the transition.

This module uses an approach to transitions away from life-prolonging treatment in the ICU that is based on acknowledging the losses involved in giving up the current plan and an open discussion of patient values. The communication task described here generally follows a discussion of bad news—the treatment is not working (the patient is getting sicker), or the side effects of treatment outweigh the current or future benefits. The question is: what do we do next? In this module, we provide tools for talking to surrogates about the patient living for a limited time and what this life could mean. These tools include learning to discuss prognosis, key questions for eliciting patient values, an understanding of common surrogate responses to news that can be devastating, and domains of good end-of-life care that intensivists can use to help family members and loved ones think about the future. The goal of the module is to switch the conversation from purely discussion about treatments to a discussion about what the patient would have wanted given their current situation.

### **Recommended Procedures:**

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**1. *Identify the legal surrogate decision maker and how the family wants to make decisions.***

From a legal point of view, the question is, who is the legally valid surrogate. By this we mean the person who has the legal authority to make decisions for the patient if the patient lacks capacity. The first step is to determine if the patient has appointed a health care durable power of attorney (DPA). If so, this is the legally valid surrogate. Secondly, many states have laws defining surrogates if the patient has not said who s/he wants to be her DPA. Typically, these laws name one's spouse first, then one's parent or children and so forth. However, every state has its own specific laws; therefore, it is wise to establish what the law is in your state.

Morally, the decision about who is the surrogate is based on two questions: 1) who knows the patient best and 2) who cares the most about the patient's best interest. The idea of "knowing the patient best" means, who can best represent the patient's values. The optimal means of representing the patient's values would be having had conversations with the patient about his/her values and choices when faced with critical illness. If no one has had conversations about these matters, next best is knowing the patient well enough to be able to understand the patient's general values and how those values might be applied in medical situations. That is, know "what kind of person Dad was and what he liked and disliked" what would he say. In those cases, where it is unclear what the patient would have wanted, the surrogate should make decisions based on the patient's best interest. Given we do not know a lot about Dad's specific views, what, given the family's or cultural views do they think is best for their Dad (obviously, given the less data we have about Dad's views about the specific outcomes or treatments he faces, the more the family's decision is about best interest).

"Caring the most about the patient's best interest" assumes that those who care the most deeply about the patient will take the most time in making a decision and will make decisions that are best able to promote the patient's interest. Given these two principles, the surrogate should be the person who knows the patient the best and cares the most about their values.

In many cases, there is not one surrogate but a number of them. Many patients do not want to choose one family member to make decisions for them, they want the family as a whole to discuss and agree on the treatment plan. A mother, for example, may not want to choose between two children but instead trust both children to discuss what she would want. Even in cases in which there is one legally valid decision maker, the surrogate may want other family members' input and agreement on the plan. By hearing what everyone thinks the patient would want, the surrogate can feel more comfortable in the decision, defray feelings of responsibility, and/or keep peace in the family.

- 2. When talking to surrogates assess their knowledge and then provide information about the current medical information:** The **SPIKES** technique (See Module 2 for additional information.) can be used to provide bad news about the patient's current situation:

**S = SETUP:** Ensure you have the medical facts, find a private setting for discussion; make sure the appropriate people are at the meeting.

**P = PERCEPTION:** Check family understanding of patient's status: *"I want to make sure we are all on the same page regarding what is going on with your Dad. Can you tell me what people are saying about his medical situation?"*

**I = INVITATION:** Ask what the family wants to know: *"Can I bring you up to date about my view of what is going on with your Dad?"*

**K = KNOWLEDGE:** Provide the family with knowledge about the clinical situation. It is important that you discuss, at least briefly, what you have tried and explain that it is not working. Discussing what you have tried is important to families who need to understand that they (and you) have worked hard to support their loved one achieve their loved one's goals. It is also important that you foreshadow for the family that this conversation will be different from the other meetings in which you discussed the patient's problems and then told them about how you planned on fixing the problems. This means warning the family: *"We need to step back and talk about the overall goals and plans. Despite all our efforts, the treatment is not working"* or *"I am beginning to worry that the consequences of our treatment plan outweigh its possible benefits"* or *"Even if the treatment works, I am beginning to worry about your loved one's quality of life."*

There is a tendency for both intensivists and family members to want to minimize the awkwardness and sadness of treatment failure by moving directly into the next treatment option. However, before talking about the next step, it is important to allow the family members to grieve the loss associated with this bad news.

#### *Talking about prognosis*

An important topic that needs to be discussed is the patient's prognosis as this helps the family decide if their loved one would think it is "worth it" to proceed with the current treatments. Many physicians do not discuss prognosis directly and when they do, there is

considerable variability in how this is done. When it is discussed it focuses more on prognosis for quality of life than prognosis for survival. Recent studies suggest there is no difference in comprehension comparing numeric expressions of risk, (e.g., “90% of people as sick as your mother do not survive”) to qualitative expressions of risk (e.g., “your mother is very unlikely to survive”). If prognostic information is given in terms of how a group of patients do (e.g., “out of a group of 100 patients like your mother, I would expect about 90 would not survive this”), data suggests that families are likely to think their loved one will do better because “they are better than average”. It is therefore important to explain how you came up with that prognostic estimation. Talking about the specific aspects of the patient’s history or response to treatments may help the family see how you are applying biomedical information specifically to their loved one. Some experts also recommend describing both the probability of death as well as the probability of survival to improve understanding.

Two other factors are important to remember when discussing prognosis. First, prognostic estimation in the ICU is inherently uncertain. Families know this and want you to discuss this. It may help to both explain the uncertainty that is inherent in all prognostication (*I wish I could predict exactly what is going to happen. We are not that smart. Some people will do better than I expect, and some will do worse*) and to tell the family the factors that you use to try to clarify your prognostication (*The first 48 hours are particularly important. We watch carefully to see how he does with the medicine we are giving him. If he is less dependent on the medicine to keep his blood pressure up and his lungs are working better, those are good things we watch for*). Finally, let the family know you are watching closely and will meet with them again to discuss any changes in the patient’s condition. (*Unfortunately, being in the ICU is a little bit like being on a roller coaster. Unexpected things happen and they can occur quickly. I do promise you, however, that if anything changes, we will touch base with you*).

Second, remember that families get prognostic information from a variety of sources. Families talk to friends, they talk to other people in the waiting room and they search the web. They may hear what you say, and still not believe it. Thus, after giving your prognostic estimation it will be helpful to:

1) Check in to see how this fits in with what they were thinking (*How does this fit into what you were thinking?*)

2) Explore where else they are getting information (*What have others told you about your Dad. Lots of people look stuff up on the web. What were you able to find there?*)

3) Attend to the emotional impact of the news if it is bad news

**E = EMPATHIZE:** Allow the family to express their emotions about the news, and pay attention to their emotions. You are telling them that the current plan is not working; this is a loss, and they will need to have time to grieve the loss. Use the principles of NURSE to attend to emotions. (See Module I.) The value of this step is to give time for emotions to be felt, expressed, and settle so that the family can think more clearly about the key questions that will follow.

**S = SUMMARIZE AND STRATEGIZE:** If you have spent some time responding to emotions, it can be helpful to find out if the family is ready to take the next step in the discussion by saying “*I wonder if we can talk about what our options are now. I need your help to consider what your loved one would say at this point in time. Is it okay to talk about this?*” If the family indicates that they are not able to go on (either verbally or non-verbally) take this as an indication that their grief/sadness is so severe that they can not consider the next steps. Do not push it. Go back to the empathize step of SPIKES, or take a break. “*I can see how overwhelmed you are. Let’s take a break and talk again tomorrow.*” When you do resume, you should begin by summarizing this conversation and again inviting them to continue.

**3. Ask key questions to elicit the patient’s values:**

**a.** You have just told the family that the patient’s condition is worsening and you are concerned that further ICU treatment may not be helpful. If the family agrees with your assessment of the situation, it is time to discuss what the patient would want given the medical situation. (See Module 7 for how to handle it if the family does not agree with your assessment) “*Given what I told you, I worry that continuing these treatments will not promote your loved one’s values. I wonder if we could talk about his/her values. An*

*important issue is focusing our attention on what your loved one would want in this situation.* ” Then try one of the following key questions:

- *“If your loved one was sitting here, and could hear what we were saying, what would they say?”* This is a key question that helps to get at the patient’s wishes. It is particularly important to focus on the patient’s goals for two reasons. First, morally the surrogate is supposed to make decisions based on what the patient would want (the ethical principle of substituted judgment). Second, surrogates often report feeling guilty if they are making a decision that temporally is related to the patient’s death. It is difficult when you feel like you are making the decision that will result in a loved one’s death. Our language even makes this hard. Surrogates feel like they are “making a decision” or that they are being asked “what they want to do” when what they want is for the patient to get better. Focusing on their loved one’s values helps them to more accurately reflect the patient’s values.
  
- *“Did Joe ever talk to you about what he would want should he get a lot sicker or the treatments stop working?”* The point of this question is to focus on Joe’s values. Other ways of doing this including asking *“Did Joe ever talk to you about living wills or advance directives? Have you ever had any family members in situations like this? What did Joe think about what should be done for them?”*
  
- Sometimes the surrogate will express uncertainty about what the patient would want in a situation like this. The surrogate will say that the patient never spoke to them about his/her values or wishes should s/he become critically ill. In these situations, one has to work with the surrogate to determine what is in the patient’s best interest. This means understanding what they liked and disliked in life and then trying to develop a treatment plan that optimizes their values. It may help to ask questions about the patient’s general values. *“What did your loved one enjoy doing? What was s/he like outside the hospital?”* Getting at the negative means asking questions such as, *“Was there anything your loved one wanted to avoid if he got sicker?” What were your loved one’s biggest fears and concerns? What would be most important to your loved one right now given the current medical situation”?* These questions try to get



at all of the patient's goals and values. A common (and understandable) response is "to get better." Given that your goal is to understand all of their values, you can answer either by saying, "What else is important" or "If this is unlikely to happen, what else would be important?" or "I wish we could make that happen. Are there other things that s/he would feel are important at this point?"

- b. Some families have not previously thought about these issues and may have trouble articulating their loved one's values. They may need some time to think about what their loved one would want. Be sure to allow for silence when asking the above questions as the surrogates may need time to think. Scheduling another meeting a few days later after the family talks about this may help.
  - c. In some instances, family members might need your help to come up with things that may be important to their loved ones other than getting "better." Of course you cannot know everyone's values, but you can assure them that, "We know from studies of patients that there are some things that most people are concerned about. Some of these are effective pain and symptom management, strengthening relationships with loved ones, relieving the burden of their illness on family, achieving a sense of control, avoiding inappropriate elongation of dying, not dying on a machine as a 'vegetable.' Do any of these things seem like they would be important, at this point, for your loved one?"
4. **Ask about how the surrogates are doing:** This is often a very difficult time for families. The data suggests that they appreciate it if you attend to their feelings and concerns. In addition, doing this can help decrease the family's stress and help them think more clearly about the questions you are asking them. Questions that attend to their feelings include, "How are you doing? How can we help you through this? What is the hardest part of this for you?"
5. **Suggest a course of action:** Once you have heard the patient's values, it is important that you articulate a course of action for the family that takes these values into consideration. It is important not to ask the family to come up with the treatment plan. You would never ask them to choose what antibiotics to use; don't ask them if they want to resuscitate their loved

one. Once you have an idea of the patient's values, your job is to tell the family what should and should not be done to promote these values:

- a. First, ask their permission to give your views. This seems like a formality but is actually a useful process diagnostic tool. If a family is not ready for a recommendation, that data suggests that you reconsider where they stand. Are they still thinking about disease status or therapy? Are the goals or values still fuzzy? In addition, some families do not want your recommendation. They believe that this is their decision and may think your making a recommendation oversteps your role or worry that if they disagree with you it will lead to conflict and impair the relationship.
- b. It is important in making recommendations to tell them what you will be doing to achieve the patient's goals. (*"We are going to work to get him off the ventilator to get him home. We are going to make sure he is comfortable. We are going to make sure he gets Sacraments of the Sick."*) Too often, when we discuss transitions in the ICU, we focus on what will not be done rather than what is done. Things to focus on include: symptom treatment plans, psychological treatment plans, spiritual support plans, and hospice or palliative care service referrals. This lets the family know that you hear and want to respect their loved one's goals.

This focus on the patient is important should the family ask you about what you would do "if it was your mom or dad". We do not hear them asking about your mom or dad's values. Instead, we hear them as asking for you to care for their loved one as much as you care for your parents. You can reframe the question to focus on their loved one's values: (*You have told me what is most important to your mom is X. Given this, if it was my mom, I would do Y. Does that make sense?*)

- c. Tell the family about symbolically important things that you will not be doing because they do not accomplish the patient's goals (for example CPR, putting the patient back on the ventilator). The general principle is to present treatments that the family would know about as decisions.

An example of how to explain this would be, "*Given what you have told me about your dad, I think that if his heart stops that we should not do CPR. It is very unlikely that he will survive this and get home with the quality of life he wanted. Instead, we are going to focus on continuing the other treatments in hopes that he may get better and get home.*"

*And we will also do everything we can to make sure that he is comfortable throughout his ICU stay.”*

**d.** Check in with the family to see their impression of your recommendation (*What do you think of what I suggested?*).

**6. Sometimes given the patient’s goals, you and the family will decide on a time-limited treatment trial.** In these cases, you want to either continue or start a treatment for a limited amount of time to see how the patient responds. It is important when you discuss time-limited trials with families that you a) tell them what the treatment is, b) the goals that you are looking for the treatment to achieve and c) what you will be looking for to determine whether those goals are being achieved d) over what period of time to see if the treatment “works or not.” Reaching an agreement about points b) through d) is very important. One might say *“We agree that while your Dad would not want to stay on the ventilator forever, that he would want every chance to see whether he can get better. It makes sense to give it another week to see how his lungs do. Hopefully things will improve. However, if things do not get better, then we should seriously consider whether our current treatments are meeting his goals. Does this make sense?”*

The key is to focus on the relationship of the treatment and the time, to the patient’s goals. Thus, for example, you might say, *“Given what you said, your Dad was the kind of person who would be willing to go through aggressive treatments if we thought he would be able to wake up and talk with you. It is often hard to tell what will happen after a large stroke like his. I recommend that we put him on a breathing machine to give his body a chance to tell us how he is doing. In four days, we will be able to tell you more about what his brain is likely to do. If his brain is not getting better, then, given his goals and values, I think that we should consider stopping the breathing machine. Does this make sense?”*

In some cases, what the family wants (or thinks their loved one would want) differs from what you think should be done. These conflicts cause a great deal of distress in the ICU and we have thus devoted an entire module on conflicts. (See Module 7.)

## Pearls/Ideas to Facilitate Conversations about Transitions

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- 1. *Invite the conversation:*** Do not force your agenda. If the family is too emotional about the bad news, give them time to grieve before moving on. If they are having trouble deciding what their loved one would want, give them space. If they are hesitant in talking about the issues, give them time during the conversation when there is silence so that they can think. Sometimes a helpful question is, “*Could you tell me what you are thinking about now?*” This may help the family voice an underlying concern.
- 2. *Respond to emotion, especially hope:*** Some surrogates perceive withdrawing or forgoing treatment as a kind of giving up hope. But hope can be directed toward many things, and it can be helpful to direct the family towards other things for which they can hope in the context of their loved one’s illness. Before redirecting hope, it is important to acknowledge the importance of what has been lost.
- 3. *Respond to guilt and feelings of responsibility:*** Sometimes family members will say, “*My mom would never have wanted this but I cannot tell you to stop. I want her to get better.*” The surrogate is saying two things. First, they are telling you what the patient would want (and thus the right thing to do). They are also telling you, however, that they are feeling guilty. It is important in this situation to acknowledge how hard this is and that you do not expect them to make a medical decision. One might say “*I do not expect you to tell me to stop. That is not what daughters say. Your job is to tell me what your mom would want. My job is to say, based on what your mom would want, what should be done. I see how hard this is for you, and I do not want you to feel like you are responsible for making medical decisions for your mom.*”
- 4. *Reaffirm your commitment to the patient/family:*** This requires both verbal commitment “*I will stick with you through this*” and non-verbal commitment, (e.g., look the family in the eye, return phone calls, help the family work through the system of care). Demonstrating non-abandonment by being willing to be with patients and family who are distressed is a powerful sign of commitment and caring.

5. ***Give the family some time to think about what you said:*** Bad news is hard to hear and the family may need some time to cognitively come to grips with the information. It is better to let a family, which is having trouble transitioning, sleep on the information rather than pushing for a ‘decision’ today. Remember that transition conversations are really two conversations: (1) hearing the bad news that things are not going the way we wanted and (2) coming up with a new plan. If one does not have time to grieve the loss, it is hard to think about the future. In addition, some families have never really considered their loved one getting worse and thus need the time to think about what s/he would want.
  
6. ***Praise the patient and family for their work up to this point:*** Clinicians tend to focus on what patients are doing wrong or not doing. During a time when families feel vulnerable, it is important to build your alliance with them by recognizing explicitly what they are doing well.

There is data that using these kinds of statements improves family satisfaction and well being. Stapleton et al. (*See Readings and Resources List.*) have been audio taping family meetings to see what behaviors are associated with higher family members’ satisfaction. For example, they have found that an increased proportion of time that family members talk (as compared to physicians) is associated with higher satisfaction ratings. In a later study, they found that three empathic behaviors are associated with satisfaction: a) assurances that the patient will not be abandoned before death; b) assurances that the patient will be comfortable and will not suffer; and c) support for family's decisions about end-of-life care, including support for family's decision to withdraw or not to withdraw life-support.

These communication tasks were developed into the mnemonic **VALUE**:

**V = Value** and appreciate what the family said, (*“I really appreciate your coming to the meeting today.” “Your help in telling us about your brother’s values are really important to us developing the best plan for him.”*)

**A = Acknowledge** the family’s emotions, (*“I know this is not what you were hoping to hear.” “I see how overwhelming this is for you.”*)

**L = Listen** to the family’s description of the patient and

**U = Understand** the patient as a person, (“*Tell me what your Dad enjoyed doing.*” “*What would your dad think of all this?*”)

**E = Elicit** and ask questions of the family, (“*What concerns do you have?*”)

**VALUE** highlights some of the same skills that we have stressed with different acronyms in Modules I and II. The fact that different authors have identified the same skills as critical emphasizes their importance.

The mnemonic above was studied in a randomized controlled trial of 126 critically ill patients cared for in 22 ICUs. After conferences in which clinicians used the VALUE statements, 95% of family members in the intervention group reported that they had been able to express their emotions to the ICU clinicians, as compared to 75% of family members in the customary practice group. In addition, among family members who initially disagreed with the decision to forgo life-sustaining treatments, those in the VALUE group were more likely to concur with the decision at a later time. Finally, 90 days after the family meeting, those in the VALUE group had less anxiety and depressive symptoms than those in the control group. This study shows that specific communication tasks and skills can lead to better family outcomes.

### **Pitfalls /Common Barriers to Good Communication**

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- 1. *Responding to family distress by reflexively offering more aggressive ICU care:*** These conversations may be distressing to families. It may be easier to just offer more treatment because it avoids emotional distress associated with this conversation. While this may temporarily calm everyone down, it evades the real issue and, in the end, you will still need to have an end-of-life planning conversation. Thus, even if you agree to more treatment you will still need to talk about things not going well and the likelihood they will not. This means learning to empathically respond to the family emotions.
- 2. *Talking about procedures like CPR before discussing the big picture of disease status, patient values, patient and family wishes:*** When serious conferences start with a discussion of code status, family members are likely to feel that something important is being withheld, and they will often respond by resisting. Patients pick up verbal and non-verbal clues to

physician attitude and skill, as demonstrated by the six types of physicians that patients named in a qualitative study of patient-physician interactions:

1. The inexperienced messenger
2. The emotionally burdened
3. The rough and ready expert
4. The benevolent but tactless expert
5. The “distanced” doctor
6. The empathic professional

3. ***Watch yourself for distancing behaviors:*** When the family shows emotion, be careful to not withdraw or change the topic and focus on biomedical issues.
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## CRITICAL CARE COMMUNICATION (C3)

### MODULE IV

#### TALKING ABOUT RESUSCITATION PREFERENCES

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*These learning modules for intensivists have been developed based on the success of communications skills modules for oncologists, which are available through Oncotalk at <http://depts.washington.edu/oncotalk/learn/modules.html>*

In this module the term ‘family’ is used to refer to all the people who are emotionally intimate or biologically connected to the patient. Thus a patient’s ‘family,’ for our purposes, may include an unmarried partner, a close friend, and/or a second cousin—in addition to a spouse, children, or parents.

#### **Learning Objectives**

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By the end of this module, participants should be able to do the following:

1. Describe four myths regarding conversations about attempting CPR.
2. Describe an argument for why conversations about resuscitation preferences should focus on goals rather than specific life sustaining therapies.
3. Describe a six-step approach to discussing the goals of therapy and resuscitation preferences in the intensive care unit (ICU) setting.

#### **Why is This Topic Important?**

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Intensive care therapy is designed to help promote patient-centered goals: the prolongation of life, decreasing symptoms, and promoting quality of life. Physicians are urged to talk to patients with life-limiting illnesses about these goals because they vary from patient to patient, and how a patient balances these competing goals may change over time. As patients get sicker, their prognosis and expected quality of life may worsen. In these cases, physicians may feel that it is important to talk to patients and families about ICU interventions that are unlikely to accomplish patient-centered goals.

Talking about Cardio-Pulmonary Resuscitation/Do-Not-Resuscitate (CPR/DNR) orders is the paradigmatic example of such a treatment. CPR is the last therapy a patient can receive before being declared dead. It therefore has obtained symbolic meaning as the ultimate “life prolonging” therapy.



It is less clear that CPR is a medically unique treatment in the ICU. Often, patients who are getting sicker in the ICU are already on multiple pressors and receiving ongoing advanced resuscitative efforts. In these circumstances, it is unclear how much CPR adds to a patient's survivability.

Despite this, CPR is symbolically important for both providers and patients. Intensivists have strong feelings about performing CPR in patients who they think have a poor prognosis, as it evokes feelings of mutilating bodies. Conversely, families view CPR as the only thing that can stave off their loved one's death. They overestimate CPR's success and overemphasize its life prolonging effect and thus demand that physicians try. These competing views may lead to conflicts over discussions of CPR order.

The purpose of this module is to discuss some of the myths surrounding conversations regarding resuscitation preferences (DNR orders) and to suggest a discussion model that tries to avoid these conflicts by focusing on the goals of therapy rather than the intervention.

### **Critical Theoretical Considerations in Discussions about Resuscitation preferences**

**1. What people care about regarding CPR:** Patients do not want CPR, e.g. it has no intrinsic value. People are willing to go through CPR because they want the outcomes they think are likely to result from CPR. Tomlinson and Brody argue that conversations about CPR should focus on the following:

- a. ***The patient's pre-CPR quality of life:*** This is an important variable as a patient's life post-CPR is not likely to be better than it was pre-CPR. Thus if a patient was not happy with his/her quality of life before CPR, s/he is unlikely to be happy with it after CPR.
- b. ***The patient's post-CPR quality of life:*** In studies, most patients do not want CPR if after CPR they will not be sentient. This shows that for most patients, post-CPR quality of life matters. Therefore, it is important for intensivists to know the data about CPR outcomes. For example, contrary to expectations, patients' quality of life post-CPR is fairly close to their pre-CPR quality of life.

- c. ***The probability of the CPR “working”:*** Studies show that patients are likely to overestimate CPR’s success rate. Thinking CPR is likely to work leads patients to want it. Studies have shown that when educated about CPR success rates, over 50% of patients changed their mind about whether they would want it. Again this fact emphasizes the importance of intensivists knowing the most recent data on CPR’s effectiveness.

The above factors are the rational reasons why one might be willing to go through CPR. The symbolic view of CPR, however, may be just as important to family decision-making. Symbolically, CPR means life. Not doing CPR means the patient is going to die. Raising the issue of CPR may make the patient’s dying more real for the family, leading to an emotional reaction. Empathy, rather than giving facts, is most likely to help the family cope with this information.

2. **You do not need to ask patients about every component of CPR or ACLS:** The purpose of discussing CPR is to make sure that decisions reflect and promote patient’s goals. This is why doctors do not ask about what antibiotic a patient wants to treat pneumonia. There is no reason to think patients care about whether they get fluroquinone or penicillin. They want the doctor to choose the drug that is most likely to achieve their goals. Similarly, there is little reason to think that patients care about whether they get vasopressors or anti-arrhythmias. From a patient’s point of view, these are just medicines that go through his/her veins.

When doctors ask patients about every component of CPR or ACLS, they are likely to perceive these different choices as real options about which they should have a preference. They come up with answers, based not on deeply held values but on what they guess they would want. These answers may lead to “irrational” medical decisions, (e.g., wanting CPR but not vasopressors or CPR but not intubation), which puts you as the doctor in the position of having to try to talk patients out of their answers. This may lead patients to wonder why you asked. Moreover, psychological data shows that people irrationally commit to decisions they have made leading to conflictual conversations.

3. Some people think that they have to ask the patient about every possible intervention listed on your hospital's code status form. This is not true. The purpose of the conversation is different from the purpose of the form. The conversation is focused on the patient's goals and values (what you are hoping to accomplish). Based on those goals, you then can suggest the treatments that will help achieve those goals or should be avoided because they can not meet the patient's goals. The code status form is designed to promote seamless care in times of emergency. When a patient is coding, there is no time to read about the patient's values. You want to be able to quickly look at a form and know what you can and cannot do. Talking about the all the therapeutic options listed on the form to the family confuses the goals of care and the means by which one tries to achieve the goals.
4. It is more helpful to think of the DNR discussion as an attempt to understand the patient's goals (e.g., what is an acceptable quality of life for the patient and what is s/he is willing to go through to get to that point.) After understanding these issues, you can then make recommendations to the family about what will help achieve their loved one's goals and what treatments are unlikely to achieve these goals and thus should not be undertaken. (*See Readings and Resources List.*)
5. If the conversation is about goals rather than treatments, "yes" and "no" answers to specific treatments are less helpful than the "whys." The following are some ways to get at the "whys:"
  - a. *"Tell me more about what you are hoping for if we do X? What do you think will happen?"*
  - b. If the patient or family says s/he wants CPR in his or her current health status, ask, *"What if something horrible happened, and you had a stroke and we thought you were never going to wake up? Would you still want X?"* (Most patients will say no). Then you can ask about this (*"Tell me why not"* OR *"Tell me about that."*) This will then lead to a discussion of quality of life considerations.
  - c. If the patient says they do not want to be on a ventilator, ask, *"Do you not want to be on a ventilator even if I thought it was only going to be for a week and then you*

6. Therapeutic decisions are typically viewed in a hierarchical fashion from aggressive (CPR or mechanical ventilation) to less aggressive (IV medications in the hospital) to even less aggressive (oral medications at home).
  - a. If patients or surrogates want to forgo ventilation, you probably do not have to ask about CPR. It almost surely does not make sense, and you can tell them that given their goals, CPR would not make sense, and you would not do it.
7. **Conclusion:** Conversations about “code status” are really broader conversations about patients’ goals and what we can and cannot do to accomplish them.
  - a. Make sure the focus is on how to achieve the patient’s goals rather than just on what is not going to be done to achieve his/her goals.

### **Talking to Patients/Families about Resuscitation Preferences**

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#### **1. Setting the Stage**

- a. *Assess the family’s understanding of the patient’s illness.* It is unlikely that a family who believes the patient is going to live forever will come to the same decision as a family who understands their loved one is dying. Therefore, being clear about what the family understands about their loved one’s illness is important to knowing how to proceed in this type of conversation.
- b. *Ask if the family is willing to talk about what happens if things do not go well.* (“We are trying to treat this infection and hopefully we can pull him through this; however, we cannot be sure. So, I want to talk to you about what happens if things do not go well. Is that okay?”)

## 2. Ascertain the Patient's Goals

- a. *“Have you ever talked to your loved one about what happens if things don't go well” or “I wonder if we could talk about what happens if things don't go the way we would like them to go. Can you tell me what your loved one would say in such a situation?”*

Other less direct ways to get at the patient's values include questions such as *“When your loved one's dad was sick, did s/he ever talk about what he/she would want if he/she became that ill?”*

- b. If you are talking to the patient, you can ask general questions about the patients' values such as:
  - *“As you think about the illness, what is the best and the worst that could happen?”*
  - *“What makes life worth living for you?”*
  - *“Would there be any circumstances under which you would find life not worth living?”*
  - *“Have you seen or been with someone who had a particularly good death or a particularly bad death?”*
  - *“How do you think about balancing quality of life with length of life in terms of your treatment?”*

Alternatively, one can ask the patient or surrogate about specific interventions. The goal is to go from these specific to a more general discussion of values and goals.

## 3. Talking about Intubation and Resuscitation to Understand Values

Remember the goal here is to understand the patient's values, what his/her pre-CPR quality of life was like, what an acceptable post-CPR quality of life would be like, and whether the patient would be willing to undergo CPR given a low probability of success. The following questions may help when one is talking to a patient, and they can be modified when talking to a family to ascertain the patient's values:

- a. *“Suppose you suddenly became very sick, and the doctors thought you only had a 5% chance of getting better enough to leave the hospital. It would require you to be on*

*machines and have a tough time for a week or so. Some people would want to try and see if they could get well enough to go home, while others would say that it is not worth it if there is a 95% chance they would not survive to go home. What do you think?”*

- b.** *“What if something happened and you could not breathe. Typically in these cases, we have to put people on a respirator, a tube that goes down their throat and then is connected to a machine that breathes for them. What would you think if you needed this?”*

If they say they would not want this, ask, *“What if I told you that you might only need it for a week or two and then you would get better enough to go home? Would that change how you feel?”* Probe for reasons and rationale.

- c.** If the patient says s/he would want to be on the machine, ask, *“What if the reason you needed the machine is that you had a large stroke, and I thought you never were going to wake up. Would you still want to be on a breathing machine?”* Probe for reasons and rationale. The key is to focus on the “why.”

The underlying principle is that the discussion should move back and forth among preferences for specific treatments, information about the treatment implications and the patient’s values, ensuring that the patient or surrogate understands the implications of his/her decisions regarding specific treatments and the physician understands the patient’s values. Identify what life situations the patient would find unacceptable (e.g., *“being a vegetable on a machine”*).

It is also important to discuss probabilities inherent in medical treatment and ask how the patient would manage uncertainty; the decision-making data suggests that one should frame the information in both positive and negative terms. *“Sometimes you cannot tell what is going to happen with treatment. Some people would want to keep trying even with a very low chance—say 5%—that the treatment will work, while others say that if 95% of the time the treatment will not help, they do not want to go through it. What do you think about this?”*

#### 4. Make a recommendation

Once you understand the patient's values and goals, it is important that you make a recommendation regarding what you think should and should not be done. The key here (*as emphasized in Module III on discussing goals when the patient is not doing well*) is to spend as much time talking about what you WILL do to achieve the patient's goals as what you think should not be done.

Emphasize that you will be there and remain actively involved regardless of what goals the patient wants to pursue.

Recognize that your recommendation may lead to negative reaction. Families might say, "*You can't do that, you have to do everything.*" Unfortunately, it is easy to hear this response as the end of the conversation. We assume that the family wants all possible life prolonging treatments and either argue with them that it will not work or grudgingly withdraw from the conversation.

Instead, try to hear the request for "everything" as a distress signal that requires more exploration. Often, "doing everything" is often not about the medical facts. The family may be saying they don't want their loved one to die, which is an emotional reaction. It represents a reluctance to face painful emotions connected with the patient's loss of health and potential impending death, preferring instead to keep hope alive by avoiding any such discussion. Or it may be tied to their worry that treating physicians will be less vigilant if they do not request all possible interventions. When doctors talk about stopping "aggressive treatments" and focusing *only* on comfort, families may fear that the doctor is abandoning them. It may even touch painful spiritual or religious issues, wondering how a caring God could allow such a tragedy to happen. It may help to attend to the family's emotions and explore what they are worried about rather than cognitively explaining how "everything" is not likely to work.

**Table 2**

**Potential underlying meanings of “everything”**

<b>Domain</b>	<b>Concept</b>	<b>What might be asked</b>	<b>What “do everything” might mean</b>
Affective	<ul style="list-style-type: none"> <li>Abandonment</li> <li>Fear</li> <li>Anxiety</li> <li>Depression</li> </ul>	“What worries you the most?” “What are you most afraid of?” “What does your doctor say about your prospects?” “What is the hardest part for you?”	“Don’t give up on me” “Keep trying for me” “I don’t want to leave my family” “I’m scared of dying” “I would feel like I am ‘giving up’.”
Cognitive	<ul style="list-style-type: none"> <li>Incomplete understanding</li> <li>Wanting reassurance that best medical care has been given</li> <li>Wanting reassurance that <b>all</b> possibly life prolonging treatment is given.</li> </ul>	“What are your most important goals?” “What is your understanding of your condition/prognosis?” “Tell me more about what you mean by “everything”” “What are you hoping for?”	“Do everything you think as a doctor is worthwhile” “I didn’t understand I was that sick!” “Don’t leave any stone unturned” “I really want every possible treatment that has a chance of helping me live longer.” “I will go through anything regardless of how hard it is.”
Spiritual	<ul style="list-style-type: none"> <li>Vitalism</li> <li>Faith in God’s will</li> </ul>	“Does your religion (faith) provide any guidance in these matters?” “How might we know when God thinks it is your time?”	“I value every moment of life regardless of the pain and suffering (which has important meaning for me)” “I will leave my fate in God’s hands; I am hoping for a miracle; only He can decide when it is time to stop.”
Family	<ul style="list-style-type: none"> <li>Differing perceptions</li> <li>Family conflict</li> <li>Children or dependents</li> </ul>	“How is your family handling this?” “What do your children know?” “Have you made plans for your children (other dependents)?” “Have you discussed who will make decisions for you if you cannot?” “Have you completed a will?”	“I cannot bear the thought of leaving my children (wife/husband...)” “My husband will never let me go...” “My family is only after my money.” “I don’t want to bother my children with all this.”

Modified from Annals of Internal Medicine 2009.

If the family continues to disagree with your recommendation, do two things: First, try to determine if the disagreement is with your assessment of their loved one’s values. It may be that you misunderstood what the patient values. Second, in some cases, you have the values correct, but you misunderstand what the patient would be willing to go through to achieve these values. In those cases, it makes sense to discuss a therapeutic trial. (See Module on Conflict)



## 5. Closing the Conversation

Some of the following phrases might help bring your conversation with the family and or patient to a close:

- a. *“I want to thank you for helping me understand your (loved one’s) values and goals.”*
- b. *For patients, “If something should happen to you, and I could not talk to you about these in more detail, who would you want to help me make these decisions? Have you ever spoken to them?”*
- c. *“I want to thank you for helping me understand your position if you should get sicker. It has been very helpful to me. I know that in the past, you have not given this very much thought. Would you be willing to think a bit more about what we spoke about today, so we can talk some more the next time?”*

Express your appreciation for their willingness to talk about the topic, and mention your on-going support for the patient and family.

## 6. Documentation

Be sure to document your conversation. State the context of the discussion, goals discussed, and decision made or still pending. Also document when the next conversation will occur.

### Pitfalls

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1. **Focusing on interventions without trying to understand the patient’s preferences or rationale:** Families and patients often feel that they are being offered an intervention that the doctor must think helps or else *“why would they offer it?”*
2. **Trying to explore goals and future decisions at the same time you are giving bad news:** It is hard to think/make plans about the future when you are dealing with the “here and now.” If at all possible, try to avoid giving bad news and asking people to make big decisions in the same sitting.

3. **Expecting families to make a decision the first time the topic is discussed:** Often discussions about goals are helpful because they get the family thinking about what their loved one might want in the future. However, it may be unrealistic to expect the family to reach a decision the first time you bring up the subject. You have dealt with these topics for years; it may be the first time they have had to think about their loved one dying. Raise the issue early and come back to it over time.
4. **Ignoring emotions:** These are difficult conversations and may cause sadness and other emotions. Be empathic.
5. **Forcing families to talk about the future or Resuscitation preferences when they are not ready:** In these situations the family will view you as trying to limit care and worry that you do not care about their loved one. In these situations, it is best to attend to their emotions (fear/sadness), talk about what you are doing, and how you will know if it is working.

#### **Pearls /Ideas to Facilitate Conversations about Goals of Care**

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1. **Attend to affect and provide opportunities for patients/families to talk about their values.** Remember that talking about issues surrounding death may lead to strong emotions. Attend to these emotions and praise the family for their willingness to talk to you about what their loved one would want.
2. **Avoid vague terms—and when you hear the family use them ask them to define them.** When people say, “*He does not want to be a vegetable*” explore this by asking, “*What do you mean?*” Similarly say, “*Tell me about this*” when the family talks about their loved one as a “fighter.”
3. **Ask the family about their questions and concerns.** The conversation should be a dialogue not a lecture.

4. **Remind patients/families that they don't need to make an immediate decision and can always change their mind.** If this is the first time they have heard about these topics, they are likely to need some time to think about it and grieve the bad news.
  5. **Ensure shared understanding of the goals of care by asking "why" when patients/families ask for specific treatments or express their goals.** Remember it is not the treatment; it is the values underlying the treatment. Finally, restate your understanding and ask patients/families to confirm that you've got it right.
  6. **Remember that you are offering to let people talk about this issue, not forcing them to "give up."** If the family is not ready, do not push. Attend to their emotions, and try to understand why this loving family sees the world differently from the way you do. (*See Module I on NURSE and responding to emotion*).
  7. **Remember to talk about the positive things that you can do to help the patient accomplish their future goals.** It might help to conceptualize these conversations like going to AAA for travel-guides/itineraries (at least it helps us). You want to find out where they want to go and what they want to avoid. Also you want to know what they might be willing to go through to get to these destinations and how to handle probabilities. Understanding this, you can then make recommendations about the best treatments to help them accomplish this plan.
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# CRITICAL CARE COMMUNICATION (C3)

## MODULE V:

### CONDUCTING A FAMILY CONFERENCE

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*These learning modules for intensivists have been developed based on the success of communications skills modules for oncologists, which are available through Oncotalk at <http://depts.washington.edu/oncotalk/modules.html>*

In this module, we use ‘family’ to refer to all the people who are emotionally intimate or biologically connected to the patient. Thus a patient’s ‘family,’ for our purposes, may include an unmarried partner, a close friend, and/or a second cousin—in addition to a spouse, children, or parents.

#### **Learning Objectives:**

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By the end of this module, participants should be able to do the following:

1. Explain the purposes of the family meeting
2. Explain a cognitive road map to how to hold a family meeting
3. Explain five factors that are associated with family members’ psychological well-being
4. Describe one pearl and one pitfall for holding a family meeting

#### **Why Is This Topic or Skill Important?**

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In the intensive care unit (ICU), patients often lack decisional capabilities. Thus, intensivists are frequently obliged to discuss a patient’s status, treatments, and medical decisions with family members or loved ones. While these conversations often occur informally, at the right moment, getting the whole family into a room is beneficial. We suggest the following indications for a family conference:

- When a course of treatment needs to be changed (for example, from treatment with curative intent to treatment with palliative intent)
- When the patient cannot participate because he or she is too ill, and the medical situation is rapidly changing
- When family members disagree about the course of treatment

The family conference is well established as a communication tool. For every clinician who thinks of a family conference as a panacea, there is another clinician who believes that family conferences are a waste of time, which will accomplish little. What can we do to maximize the value of the family conference?

### **What Makes Family Meetings Hard?**

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Family conferences are hard for a number of reasons including the following:

1. Families bring complicated relationships and interactions to the meeting.
2. Family members
  - have their own motivations and interests,
  - have their own personal emotional needs,
  - have different preferences for information or decision making, and
  - may disagree about the right course of action.

Family therapists tell us that families are more than a collection of independent people. A family is an independent organism with its own way of functioning. Some families talk things out calmly, some yell and scream, and others avoid conflict. In addition, family members learn and take on roles in the family. For example, if the matriarch made all the big decisions before becoming critically ill, the daughter may feel insecure and anxious about taking on the role of making a big decision about the matriarch's life support. Data from recent studies, for example, show that significant correlations were found between family conflict and a history of family discord, younger family member's age (e.g. children vs. spouses), and being African-American.

Obviously clinicians aren't experts in family therapy, but recognizing family roles and processes as unique characteristics of a family may help you understand how to best navigate and facilitate communications with families and give you an idea of who to talk to first, who shouldn't be left out, and how to frame issues. Two background questions are especially useful. First, ask about the patient's role in the family. Second, ask how the family makes decisions (e.g., "*Tell me a bit about how your family typically makes big decisions?*") While you will not always have the luxury of knowing the answers to these questions before the family conference, remember that a

social worker, psychologist, or nurse might know the answers already. Talking to them about this information could help you function more effectively in the meeting. Table (1) outlines some of the challenges you may encounter in dealing with families of ICU patients and offers some communication tools to help you most successfully handle such challenges.

**Table 1: Communication Challenges and Tools**

Challenge	Communication Tool
<i>Family dynamics</i>	<ul style="list-style-type: none"> <li>• Ask how the family makes decisions</li> <li>• Pay attention to family roles</li> <li>• Look at how the patient’s role has changed</li> </ul>
<i>Troublesome family members</i>	<ul style="list-style-type: none"> <li>• Remain neutral; avoid taking sides</li> </ul>
<i>Divergent opinions</i>	<ul style="list-style-type: none"> <li>• Set up ground rules and boundaries for the discussion</li> <li>• Name the disagreement</li> <li>• Focus on the patient</li> <li>• Reframe the disagreement neutrally</li> </ul>
<i>Strong emotions</i>	<ul style="list-style-type: none"> <li>• Acknowledge the emotion in the room</li> </ul>

Similarly, watching how the family interacts in the meeting may give you clues about how they function. Observe whether the family members talk about themselves, whether the conversation is respectful, who is involved, whether questions focus on a single topic, and who keeps talking when there are interruptions. When they disagree, can they do so openly by explaining their reasoning or do they become emotionally abusive? How they deal with emotions is also instructive. When a family member becomes emotional, do the others react empathically or dismissively? Do they seem to take care of each other and provide reassurance?

While insight into a family's dynamics can help with understanding family reactions, it is important to stay neutral in family interactions. It may be hard to do this, particularly if you feel that one family member is being unfair or you disagree with someone’s decision. The family dynamics, however, predate the patient's illness and reflect lifelong patterns of interaction. You will not be able to change these patterns in a single brief conference and will be setting yourself up for failure if you try. In the case of disputes, you might say, *"I can see that you all have some disagreements on a number of issues. I wonder if you could put these aside for now, so that we can try to focus on what is going on with your mother."* The principle is that you are there to

facilitate discussion focused on the patient's values, not to help the family communicate more effectively.

For families who disagree, you can be helpful by setting clear boundaries and ground rules for discussion. When there are bickering family members, it may be helpful to say *“I’m really glad that we could all sit down and talk about what is going on with your mother. Given that there are so many people, I want to try and make sure that everyone has a chance to ask their questions. To make it easier, I would like to request that only one person talk at a time. I’ll make sure that everyone gets to ask his or her questions. If we run out of time, we will set up another meeting in the next couple of days.”* Clearly stating the ground rules may help a family stay on task.

If family disagreements escalate, there are a couple of things you can do. First, point out the disagreement. (*“I see you both have strong feelings about this.”*) This may help the family members stop arguing with each other and start talking about the issues underlying the disagreement. Another option is to focus the conversation on what the patient would say, *“I see you all disagree about what you think should be done. I wonder what your mom would say if she were here?”* Third, one can try to reframe the disagreement as a neutral observer, and then, ask if they can think of a third alternative. (*“So you want to have your mom go to a nursing home because you think she would get the best care there. Your sister wants her to go to her house because she thinks she will be happier. I wonder if there is a way to both make her happy and give her the best care.”*)

Finally it is important to check in about what information they want. The only way to know who wants what information is to ask specifically before you give information about which people may have different needs and opinions. For example, in a family meeting where the patient is being taken off a ventilator, one might turn to the family and say, *“Some people want to know what happens after we turn off the ventilator. Other people do not want to hear this. Is this something that would be helpful for you to know?”* This gives different family members the opportunity to express their own needs about how much information they want. Variations in how much information family members want should be explicitly negotiated.

## **Roadmap: Conducting a Family Conference**

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1. Prepare for the conference (participants, room with privacy, clear purpose)
2. Introduce everyone present and the purpose of the meeting
3. Assess what the family knows and expects (**Ask-tell-Ask**)
4. Describe the clinical situation (**Ask-Tell-Ask**)
5. Ask the family for questions and concerns (**Ask-Tell-Ask** and **NURSE**)
6. Propose goals for the patient's care, and be prepared to negotiate (See Module VII Addendum A.)
7. Provide a concrete follow-up plan.

### **1. Prepare for the conference:**

Who should be invited? In general, all family members should be invited to attend the family conference. The only exception to this policy would be if a previously competent patient said that certain people should not be included. Inviting some family members but not others can come across as taking sides and decreases one's ability to be an impartial patient advocate.

It is also important that all clinicians involved in the patient's care are invited to the meeting. The primary care doctor may have the best relationship with the family; specific sub-specialists have data that the family needs; nurses answer questions about what was said at the meeting in the following hours; and social workers can help with complex family dynamics. A brief huddle prior to the conference will enable clinicians to deliver clear and consistent messages. One person should facilitate the meeting, to help guide who should speak at any one time. A room with some privacy enables the family to speak more freely.

### **2. Introduce all participants and the purpose of the conference:**

If you are facilitating, ask the clinicians to give their name and role in caring for the patient; ask family members to give their relationship and care-giving responsibilities. The facilitator might discuss the purpose by saying, *"I want to discuss how your dad is doing medically. I also want to make sure that you understand what we are doing for him and what we're watching for. Finally I want you to help me understand his values and goals in order to help us design his care. Are there any other things you would like to discuss?"*



One of the things that you can assess at the beginning of the conversation is whether the patient had named a single surrogate. About 20% of Americans have living wills and sometimes have named one person to serve as their surrogate. Even if there is a surrogate, however, this person may still want input from other family members. In addition, even when there is not a legally named surrogate, the family may decide that they want one person to serve as the primary decision-maker.

### **3. Assess what the family knows and expects:**

Ask the family to report what other clinicians have told them, how they think the patient is doing and what they have observed. (See Module I on *Ask-Tell-Ask*) This enables you to assess how well they understand the medical situation, how they are doing emotionally, and how you should frame your summary of the clinical condition. If a family says *“We think he is dying,”* it is likely to lead to a very different conversation than if they say, *“The doctors say he is not likely to get better, but we are still praying that he gets better. He is such a fighter.”* Ask them if they want detailed information or if they are the kind of people who like statistical information.

### **4. Describe the clinical situation:**

Begin by asking to share your perspective. Start with the ‘big picture’. While you may want to name specific parameters that will be monitored, skip detailed pathophysiology. The entire overview should take no more than a couple of minutes. If it takes longer, you probably have not prepared a clear enough message prior to the conference. Check for comprehension after you have finished by asking, *“What questions do you have about what I’ve said?”*

### **5. Ask the family for questions and concerns, and about patient values:**

After providing information, it is important to ask explicitly for questions or concerns. Different family members may have different concerns. If possible ask, *“What other questions or concerns do you all have?”* until there are no more questions. If one person seems to dominate, turn to other family members (*“Can I see if any other family members have questions?”*) Acknowledge the emotional content of the family concerns. (See NURSE in Module I.) Finally, it may help to ask

whether there is anything you can do to help the family members themselves. (*“What can we do to help you to get through this difficult time?”*)

As we noted earlier, focus on what the patient would want (*“If your dad was sitting here and could hear what we are saying, what would he say?”*) Family members may still find this question difficult to answer; we find that while they know what their loved one wants, it may not match what they want as a loved one. For example, a daughter might say, *“My dad would never have wanted to live like this, but I don’t want you to stop.”* While telling you that her dad would not want treatment focused on existence with this quality of life, she is also telling you that she feels guilty over being asked to make a life and death decision. Acknowledge this, and remind the surrogate that her role is to tell you what her dad would want by saying, *“I can understand that. I appreciate your telling me what your dad would say, so we can respect his values. And I know it’s hard when you want to keep him alive.”*

**6. Propose goals for the patient’s care, and be prepared to negotiate:**

Physicians in these conferences should make clear recommendations based on the patient’s values. Propose a plan that honors the patient’s goals first. Then you may want to talk about therapies that don’t fit. Don’t start with a long list of therapies you want to withhold.

**7. Provide a concrete follow-up plan.**

Summarize the messages that you want the family to take away from the meeting. If the discussion focused on the goals of care, the summary should focus both on consensus decisions and areas of disagreement. In addition, talk about future milestones that may affect decision making to follow. For example, if you decide to try a trial on antibiotics, it is worthwhile talking about how you’ll know if the antibiotics are working. Specify the next time you will talk to someone in the family, (*“I’ll give an update to whoever is here for rounds tomorrow.”*) Finally, if it is a large family, you should ask about who the primary contact person is to simplify communication.

## **8. Document the family meeting in the chart**

Documentation is important to ensure that all health care providers know what happened at the meeting. The key facts to document are: who was there, what was discussed, what the family said about the patient's goals, what treatment plan was decided on, what outcomes will be used to determine the plans success and when the next meeting is. It also may be helpful to document whether there was disagreement among the family as well as any strong emotions that were expressed.

### **Does Holding a Family Meeting Make a Difference?**

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Data suggests that family meetings in the ICU lead to shorter lengths of stay and decreasing ICU mortality, suggesting that discussions of goals of care are occurring earlier. In addition, recent studies show that family meetings can lead to decreased family member stress after hospitalization. The best studies show the following:

- One study found that requiring an ethics consultation and family meeting for patients who required continuous mechanical ventilation for over 96 hours resulted in more DNR orders and shorter ICU lengths of stay, while mortality did not change.
- In a study of 530 adult ICU patients whose goals were not being achieved with advanced supportive technology, a strategy of multidisciplinary meetings (within 72 hours of admission) plus follow-up meetings was evaluated. The meetings had four explicit goals: reviewing the medical facts, discussing the family's perspective on what the patient would have wanted, agreeing on a care plan, and agreeing on the criteria by which success or failure of the care plan would be judged. Length of stay decreased following the intervention, without a change in mortality. The authors suggested the regular family meetings resulted in earlier discussion of treatment goals and focusing on comfort (and away from life-prolonging) therapies in patients who were unlikely to survive ICU care.
- A trial randomly assigned 126 surrogates to receive either routine interactions with health care providers, or interactions based upon the communication strategy VALUE, described in Module III, plus a bereavement brochure. Family members in the intervention group had less depression, anxiety, and PTSD symptoms.

<b>V</b>	<b>V-alue and appreciate what the family said</b>
<b>A</b>	<b>A-cknowledge the family emotions</b>
<b>L</b>	<b>L-isten and</b>
<b>U</b>	<b>U-nderstand the patient as a person through asking questions</b>
<b>E</b>	<b>E-licit questions</b>

### **Pearls**

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1. As you practice the above steps of a family meeting, it is helpful to reflect on the specific statements that have been shown to be associated with improving family satisfaction and decreasing psychosocial distress. Curtis et al. coined an acronym: **VALUE** (See Module III) to list five specific evidence-based behaviors associated with improved outcomes: Valuing, Acknowledging, Listening, Understanding, and Eliciting.
2. Be respectful to all family members. You cannot know the family dynamics and thus cannot predict who is key in the decision-making.
3. View your role as a neutral mediator when it comes to family disagreement. In addition, if a family member shows strong emotions, wait for a minute, and let the family members be empathic to each other before you jump in. Enable the family to care for each other, and when they do this in constructive ways, acknowledge and reward them.

## Pitfalls and How to Fix Them

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- 1. *Asking family members to decide on life-sustaining treatment for a patient.*** In studies, family members are generally inaccurate in their predictions of what patients would want regarding life-sustaining treatment; this is true regardless of whether there has been a specific discussion about these matters. In making decisions for the patient, family members often confront their own hopes and fears about the patient's illness and death, placing considerable stress on the family member. We recommend asking the family to represent what the patient would have said. (*"If your mother was sitting here with us, what would she say about this?"*) One study indicates that this question yields more accurate answers, and in our experience lifts a bit of the responsibility and guilt from the family's shoulders.
- 2. *Over-focusing on the single legal surrogate decision-maker.*** Despite laws that give a hierarchical order of surrogates, many families make decisions for their loved one based on consensus. Even if the husband is the legal surrogate, the doctor typically meets with the entire family about what is going on with the patient. And while the husband may make the "final decision," he often wants to get the whole family's opinion and—if possible—agreement. We recommend that clinicians ask the patient, when competent, about both whom s/he wants as her surrogate and how s/he wants his/her larger family to be involved. If the patient is not competent, one should ask the surrogate about how the family makes decisions and, if possible, honor the family's preference.
- 3. *Overlooking the stress of caregiving.*** Family members are usually stressed, and sometimes anxious or even depressed. Family members who have been through a patient's life-threatening illness have a significant risk of post-traumatic stress disorder *related to their experiences with medical care*, and the risk of PTSD rises with the length and complexity of the illness. In one large study of patients with life-threatening diseases, 40% of the families spent all their family savings caring for the patient during the course of the study. We recommend that clinicians notice family stress, encourage family members to take care of themselves, and help mobilize supports where possible. The less stressed the family members are, the easier it will be to talk with and make decisions with them. Table (2) below outlines the pitfalls explained above along with some recommended communication tools to help you avoid such pitfalls.

**Table 2: Communication Pitfall and Tools**

<b>Pitfall</b>	<b>Communication Tool</b>
1. Asking the family to decide for a patient	1. Ask the family what the patient would have wanted
2. Focusing on a single legal decision-maker	2. Respect other decision-making models like consensus
3. Overlooking stresses of caregiving	3. Explore stresses and identify support services

In our experience, two related emotions, guilt and the fear of abandonment are particularly common in family meetings. Family members are supposed to take care of each other. American culture stresses *doing*, and thus the default for many families is to want to do more to try to improve their loved ones health. Therefore, it is important to be cognizant of your language. Asking people if they want to be “aggressive” or “do everything” intimates that choosing palliative care is “giving up.” Similarly talking about withdrawing “care” or “stopping life supports” may feel like talking about abandoning their loved one.

## Summary List of Tasks

### 1. Prepare for the Meeting

- Review medical issues and history.
- Coordinate health care team.
  - Attending, Care coordinator, SW, palliative care RN
- Discuss goals of meeting with team.
- Identify a meeting leader among the health care team.
- Discuss which family members will be present.
- Arrange a private, quiet location with seating for all.
- Try to minimize distractions: set aside adequate time and seating, turn off pager if possible.

### 2. Introduce all participants and the purpose of the conference

- Introduce all in attendance.
- Establish the overall goal of the meeting, by saying something like:
  - “Today I’d like to make sure everyone understands how [the patient] is doing and answer all the questions that you have,” or “We wanted to meet today to discuss how [the patient] will be cared for at home.”
- Ask the family if this is ok and check about what their goals are for the meeting.
  - Be careful to not start the conversation; just get the goals at this point.
- Rules for discussion (state if worried about family discord or a lot of people)
  - *We have a half an hour for discussion*
  - *We will try to answer everyone’s questions. Sometime when two people talk at once it is hard, so if one person could talk at a time it would help.*
  - *Acknowledge that this is a difficult time/situation*

### 3. Assess what the family knows and expects?

- Ask family members questions, such as:
  - *“What have you been told about [the patient’s] condition?”*
  - *Let’s begin by making sure we are all on the same page. How are you seeing the medical situation at this point? What have you been told?*
  - *What is your understanding about the likelihood of him getting well enough to return home?*
- As they tell the story think about:
  - What do they understand?
  - What do they think will happen? (e.g. what do they believe vs. what they are told)
  - What do they hope will happen? (e.g. What are their goals?)
  - What are their emotions?
- After hearing from the family, a helpful follow-up question is:
  - *“Is there anything that isn’t clear that we can help to explain?”*

### 4. Describe the clinical situation

- Ask if it is all right for you to give them some information about what is going on.
- Consider asking about how much information they want. (*Some people want to hear all the details, while other families find a lot of information is confusing and want to hear the big*

picture and then to ask questions about what they do not understand. Which kind of person are you?)

- At the end of life, some families want to hear what may happen after discontinuing machines, other do not -> so ask what they want to hear?
  - *Hints for giving information*
    - Give information about:
      - i. Nature of the patient's illness and treatments.
      - ii. What may happen next (prognosis) and what you are looking for to determine how things are going.
      - iii. Impact of treatment on patient experience, including symptom burden; potential complications of treatment; expected care needs after hospitalization.
  - Hints regarding giving the information:
    - i. You do not need to do 1-5 all at once.
    - ii. Beware of physicians' tendency to talk too much, give too much detail, lecture, and focus on technical matters, while not listening enough to how the family is responding.
    - iii. Check in with what the family has heard after each domain. *What questions do you have about what I just said?*

## 5. Ask the family for questions and concerns, and about patient values

- *I know you just got a lot of information. What questions do you have? What concerns do you have? What is unclear?*
- Families may either ask cognitive question or respond to the information with emotions.
  - Emotions are more common when having received bad news
  - If the family seems stuck try to *make sure you have attended to emotions!*
- Respond empathically to the family's emotion – **NURSE**.
- Elicit goals of all those present, especially if multiple perspectives are held.
  - Be careful with language
    - i. "Everything" and "aggressive" suggest that you are doing a lot – we are always aggressive – the question is what goals are we being aggressive towards
    - ii. You need to make decisions induces guilt vs. we need your help to understand what your mom would want (and then we suggest a treatment plan!)
    - iii. What do you want? Suggest that they make decisions and wanting is the key concept (and what they want is their loved one to get better vs. what would your dad say given what the doctors have said).
- Begin with an open-ended question, such as:
  - *Given what's gone on, what would your Dad say if he could see himself?*
  - *Tell me about your mother. What is she like? How has she dealt with this illness?*
  - *You know your father best. The information we need from you is about what your father would really want if he could speak for himself now. If your father could talk, how do you think he would want us to take care of him? I know this may not be what you think is*



*the right thing to do here or what you hope we would do, but we are not really asking you to make decisions for him, but rather to help us understand what your father would want?*

- *Did your mother ever say anything about how she felt about herself or others being put on a ventilator when they would never get off the machine? Did this sort of situation ever come up in your family? Did you talk about similar stories in the newspaper or on TV?*

## **6. Talking about what comes next (e.g. the treatment plan for the future; propose goals for the patient’s care and be prepared to negotiate**

- Achieve a common understanding of the issues.
- Find out if the patient had made his or her wishes about the decision known by asking,
  - *“Had [the patient] ever discussed what he would want or not want in this kind of a situation?”*
- Reassure family members that they are making a decision about what is in the best interests of the patient, not necessarily what is in their own best interests.
- Begin with open-ended assessments and then turn to specific interventions if necessary. DO NOT focus on machines or specific interventions until you have a good sense of the general goals.
  - *It sounds like your Dad’s primary goal was to be able to independent. If that would not happen he wanted to avoid being stuck on machines*
- Offer clear recommendations based on patient and family goals, by suggesting, for example:
  - *Given our understanding of the medical situation and what you’ve told us about [the patient’s] goals, I would recommend not pursuing dialysis.*
  - *Given our understanding of the medical situation and what you have told us about X’s goals, Dr. D could you make a recommendation about what treatments would help?*
  - Remember: we never withdraw “care.” But do not feel you need to identify every imaginable option, and do not offer treatment options that are inappropriate.
- Seek consensus whenever possible, agreeing on the decision or on the need for more information.
- Use summary statements, such as
  - *It sounds like we are coming to an understanding that [the patient] would not want to continue on the ventilator. Is that how everyone understands his or her wishes?*

## **7. Provide a concrete follow up plan**

- Offer a brief summary of what was discussed.
- Point out what is going to be done to try to achieve the patient goals.
  - Both Tx goals and dispositional goals
- Talk about what you are looking for (e.g. how will you know if he is getting better or worse).
- Ask for any final questions.
  - Encourage to ask questions as time goes along.
    - i. I expect you will have questions as you think about what we talked about. Feel free to ask me about things that do not make sense when we touch base tomorrow.*
    - ii. It is normal to think of new things after we leave. Write down questions that come to you as you think about this conversation. I can answer them when we touch base tomorrow*
- Offer a statement of appreciation and respect for the family:

- *I appreciate how difficult this must be, but I respect everyone for trying so hard to do right by [the patient], or I want to thank everyone for being here and for helping to make these difficult decisions.*
- Make a clear follow-up plan, including plans for the next family meeting and how to contact the health care team.
- Check in with the family about their needs.
  - Ask about how they are doing.
    - i. How are you all doing? I know this has been a really rough couple of weeks.*
  - Ask if there is anything you can do for them.
    - i. What can we do to help you get through this?*
    - ii. While we have spent a lot of time today planning for the future, the reality of ICU care is that sometimes unexpected things happen. I do promise you that if something happens, we will contact you as soon as possible. Do we have your home/cell numbers?*
- Check in to make sure they heard what you wanted them to hear.
  - i. I want to make sure we are on the same page. If you were going to talk to someone about this meeting, can you tell me what you would tell him or her we talked about? I want to make sure we are on the same page.*

**8. Document the meeting in the chart.**

## CRITICAL CARE COMMUNICATION (C3)

### MODULE VI:

#### DISCUSSION FORGOING LIFE-SUSTAINING TREATMENT AND THE DYING PROCESS

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*These learning modules for intensivists have been developed based on the success of communications skills modules for oncologists, which are available through Oncotalk at <http://depts.washington.edu/oncotalk/learn/modules.html>*

In this module the term ‘family’ is used to refer to all the people who are emotionally intimate or biologically connected to the patient. Thus a patient’s ‘family,’ for our purposes, may include an unmarried partner, a close friend, and/or a second cousin—in addition to a spouse, children, or parents.

#### **Learning Objectives**

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After reading this module, participants should be able to do the following:

1. Describe major challenges to discussions of forgoing life-sustaining treatment and recommendations for responding to them.
2. List preparatory steps to be taken before approaching a family of an ICU patient to discuss withdrawal or withholding of life-sustaining treatment.
3. Describe essential elements of a discussion between the ICU physician and the family of a critically ill patient about withdrawing or withholding life-sustaining treatment.
4. Describe a process for talking about what will happen during the process of withdrawing or withholding life-sustaining treatment
5. Discuss pearls and pitfalls associated with discussion of withdrawing or withholding life-sustaining treatment.

#### **Why This Topic?**

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As recently as several decades ago, withdrawal of life-sustaining treatments was considered acceptable only after brain death. Today, limitation of such treatments precedes more than 90% of ICU deaths, and discussion of this process with families of critically ill patients (and, sometimes, patients themselves) is among the critical care physician or intensivist’s regular

responsibilities. For these physicians, therefore, the core skill set includes timely, informative, and sensitive communication about forgoing life support.

Discussions about limiting therapy are usually initiated by physicians, and decisions to withhold or withdraw therapy are almost always made by surrogates, because patients are too ill to participate. Only rarely do surrogates disagree with recommendations to withhold or withdraw therapy, although in some cases, multiple meetings are held before a decision to withdraw therapy is made.

Therapies tend to be forgone in a distinct order. In a US study, the sequence of *withdrawal*, from earliest to latest, is: blood products, hemodialysis, vasopressors, mechanical ventilation, total parenteral nutrition, antibiotics, intravenous fluids and tube feedings. Reflecting health care providers' attitudes about the moral acceptability of forgoing treatments, most commonly *withheld* treatments are cardiopulmonary resuscitation (CPR) and mechanical ventilation.

Most families do not know what dying looks like when life-sustaining treatment is withdrawn in an ICU. Having decided to focus on comfort, they know that their loved one may die; however, they may not know how this will happen, or what they should do. Providing this information can help ease what is a difficult time for families. During this emotional time, there are a number of things that the doctor can say that will relieve family members' suffering. There are data, for example, that show that family members who felt more prepared for the social, religious and practical aspects of their loved one's death have less psychological morbidity afterwards.

### **What Are the Major Challenges to Discussions of Limiting Life-sustaining Treatment?**

Families often have specific concerns/misconceptions about limiting life-sustaining treatments. These include the following:

- 1. Families may perceive the decision to forgo life-sustaining treatment as the cause of death, with accompanying burdens of responsibility and guilt.** Because of the close temporal correlation between limitations of life-prolonging therapy and the patient's death, family members often worry that "they are causing the death."

**RESPONSE:** Given this, it is important that discussions of limitations of life-sustaining treatments focus on the goals of therapy rather than the therapy themselves. Families also need to be reassured that it is the underlying illness, not the stopping of the machine that is the cause of death. (*“Unfortunately, your dad’s lungs have just stopped working. The machines are artificially maintaining things, but they are not going to get better. Turning off the machines is respecting his wishes and letting his body die naturally.”*)

- 2. Families may fear that limitation of life-sustaining treatment will be accompanied by intractable suffering including severe pain or dyspnea.** Family members often believe that discontinuation of mechanical ventilation and other life-sustaining treatments is inevitably accompanied by intractable suffering (e.g. sensations of suffocation, intense hunger or thirst, etc.). This fear makes it hard for them to turn off life-sustaining machines. These beliefs have many origins—the public media, previous experience, or conversations with family or friends. A common reason for this belief is that they saw their loved one suffer prior to intubation. Because opiates were not given, they do not know they can be given now to relieve distress.

**RESPONSE:** With good palliative care, families can be reassured that patient’s symptoms can be well controlled. In addition, the time from forgoing life-sustaining treatment to death is usually short. It is important to reassure the family of these facts and let them know that you will be there to relieve symptoms. (*“Before we turn off the ventilator, we will make sure your dad is comfortable. Also we will be there watching him closely and making sure that he is comfortable throughout this process.”*)

- 3. There is a fear that limiting life-sustaining therapies raises ethical or legal concerns.** *Health care providers* may worry about their legal liability. They also may worry that treating patient symptoms involves giving medicines that shorten the patient’s life and thus are considered euthanasia. *Families* may also worry about the ethical issues associated with these decisions. In particular, while they may find it acceptable to not start a therapy, stopping interventions often feels like they are causing their loved one’s death.

**RESPONSE:**

**Medically**, a variety of case control studies have found either no or little correlation between opiate or benzodiazepine dose and time to death.

**Legally**, a consensus has developed over the last 30 years:

- a. There is no legal distinction between withholding and withdrawing of therapies.
- b. Decisions to withhold or withdraw medical interventions are usually made in the clinical setting, and courts rarely need to be involved.
- c. When patients die after they request that life-sustaining therapies be withheld or withdrawn, their death is considered neither homicide nor suicide, and their providers are not held liable.

The **ethical** consensus matches the legal one. First, decisions on whether to use life-sustaining treatments should be based on their benefit/burden ratio—that is whether the treatment’s ability to promote the patient’s values outweighs its side effects. Various other moral distinctions used in the literature, including, the difference between acts and omissions, whether a consequence of treatment is intended or merely foreseen, and the difference between ordinary and extraordinary treatment are not useful in guiding clinical practice. Second, when a patient cannot weigh a treatment’s benefits and burdens, the family should make this decision based on: (1) what the patient would have wanted or (2) what is in his or her best interest, given the patient’s values.

**4. Teachings of certain religions (including Catholicism and Judaism) may be interpreted as prohibiting decisions to limit life-sustaining treatment.**

**RESPONSE:** Despite variations in the relative importance of autonomy and the sanctity of life, the three most common religions in the United States acknowledge that, when a patient is clearly dying, it is acceptable to forgo certain treatments and focus on comfort. In Judaism and Islam, the sanctity of life is paramount, and patients are bound to seek healing. Thus, for example, artificial hydration and nutrition are required unless the feeding itself causes suffering. Christian bioethics places more of a priority on patient’s weighing the benefit/burden ratio and making autonomous decisions; [Catholics emphasize the importance

of distinguishing between ordinary/extraordinary therapies in their thinking about forgoing life-sustaining treatment; and in Judaism and Islam, while the sanctity of life is paramount, treatment may be forgone if the patient is dying and the treatment causes suffering. While a basic knowledge of organized religions' views toward forgoing life-sustaining treatment is useful for an intensivist, how any one patient or family interprets them may vary a great deal given their ethnic background, sociocultural status, and personal circumstances. For example, within Judaism, one's beliefs may vary depending on whether one is Orthodox or Reform. It is therefore critical to non-judgmentally inquire about the family's religious belief. (*"What are your religious beliefs about this?"*)

**5. Death is uncertain, and its timing is unpredictable after withdrawal of treatments that were initiated to sustain life.**

**RESPONSE:** While most patients die shortly after limitations of life-sustaining treatment, a few survive to hospital discharge. The median time to death from the first decision to limit therapy is approximately 15 hours in ICU patients. Following the decision to limit the most active form of therapy, the median time to death if the therapy is withheld is 14.3 hours and 4.0 hours if the therapy is withdrawn. Still, 11% of patients survive to discharge.

Families typically do not know these facts. It is therefore important, prior to forgoing treatments, to talk with them about what they are likely to see and what may happen. (*"Most patients die within hours of turning off the breathing machine. I think that is what will likely happen with your mom. However, some patients surprise us, and their bodies continue to breathe after we turn off the machines. If that is the case, we will continue to focus on keeping her comfortable, and let her body tell us what the next step will be. As we discussed, our goal is comfort, and whatever happens, we will do everything we can to make them comfortable."*)

### **Preparing to Discuss Limitation of Life-Sustaining Treatment**

- 1. Know the legal and regulatory parameters:** A thorough understanding of relevant law and policy is an essential prerequisite for any physician planning a discussion of withdrawal or

withholding of life-sustaining treatment. Although the United States Supreme Court has established certain overriding standards, state law and hospital regulations vary, and you should know your own state law. Key issues to know include: (1) what level of evidence is required to establish a patient's preference to continue or discontinue life-sustaining treatments, (2) which individuals have surrogate decision-making authority, and (3) what is the extent of this authority?

- 2. Know the Patient's Condition and Prognosis:** The significance of a decision to withhold or withdraw life-sustaining treatment cannot be overstated as it typically results in the patient's death. Family members often have many questions about their loved one's prognosis and what will happen with or without therapies. Given this, it is critical that the intensivist know—to the greatest extent possible, within the inherent limits of medical certainty—the patient's condition and prognosis with and without continuation of ICU therapies. Being in command of the medical details is important to reassure the family that you care enough to know what is happening with their loved one.

On the other hand, one cannot know everything. Most families understand this. They want to know that you will get the answer for them. (*"That is a great question. I am not exactly sure, and I do not want to give you the wrong answer. I will talk to the surgeons about this and get back to you this afternoon. Does that sound okay?"*)

In other situations, the family asks unanswerable questions, (Is there any chance he will get better? Why did this happen?) These are difficult questions, and there is not one single way to deal with them. These three general principles may help:

- a.** Attend to the emotions that underlie these questions. Often these questions are the way people express emotions—fear, sadness, frustration. Empathizing with the emotions often helps the family (*"I wish I could tell you why things have not gotten better."*)
- b.** Explore the concerns which underlie the question. Often such questions can be interpreted multiple ways. Rather than guessing what the family is asking, ask them. (*"That is a very difficult question. Can you tell me what you are worried about?"*)



- c. Provide sign posts to help the family understand your thinking. In the ICU, the prognosis is often unclear. It may help the family if you can tell them the factors you are looking for to determine how the patient will do. (*“I can see how frustrating it is not to know how things will go. What we are watching for over the next day is ... What questions do you have about that?”*)

3. **Know how to maintain patient comfort and dignity while life-sustaining treatment is withheld or withdrawn:** A skilled and attentive intensivists, assisted by an experienced critical care nurse, can maintain comfort and dignity for the patient without life-sustaining treatment. This requires the same degree of training and practice as other common ICU procedures, such as placement of vascular catheters, endotracheal intubation, and interpretation of hemodynamic parameters. In addition, maintenance of patient comfort during withdrawal or withholding of life-sustaining treatment will often require a commitment of physician and nurse time, which must be dedicated when the decision is to be implemented.
  
4. **Coordinate with other members of the clinical team in planning the process and content of the discussion:** All key members of the interdisciplinary intensive care team, including the primary care physician (if different from the intensivist), specialty consultants, and other disciplines (nursing, pastoral care, social work), should participate directly or indirectly in a discussion about withdrawal or withholding of life-sustaining treatment. Before talking to the family, the intensivist should try to organize a coherent approach by all in the group, listening to and integrating views of the various individuals. Inconsistent communication from different professional caregivers causes distress and confusion for families, impedes their decision-making, and strains relationships within the team itself. Conversely, consistency can strengthen the family’s confidence and help to relieve doubt and guilt about the ultimate decision.

## **Discussing the Decision to Forgo Life-Sustaining Treatment**

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*Many of the principles discussed here are similar to those in Module III on transitioning to care focusing on patient comfort. That module focuses more on what is done prior to the decision to forgo treatment, while this module will focus more on what is done after there is an agreement to forgo life-sustaining treatment.*

- 1. Identify the Participants in the Discussion:** The patient's legal surrogate decision maker should be present, and the basis of this individual's authority (health care proxy appointment, durable power of attorney, next-of-kin relationship) should be determined. Ideally, the patient's primary care physician, hospitalist, and the patient's nurse should also be present; at a minimum, the physician must be notified of the meeting and of the intended content of the discussion.
- 2. Find out What the Family Knows about the Patient's Illness and Current Treatment:** After introducing yourself and the other participants, finding out what the family knows about the patient's illness and current treatment is the initial step with every ICU family. A decision to forgo life-sustaining treatment must be fully informed, which requires an understanding of the patient's illness, therapies that have been used, results of the ICU therapeutic trial, and the expected outcome of continued intensive care treatment. However, many families lack basic information about diagnosis, treatment, or prognosis, even after a prolonged stay in the ICU. The physician should ask what the family knows and listen carefully to their answer.
- 3. Educate the family as needed:** If the family does not understand the medical facts, offer to provide information. (*"Would it be okay if I tell you what I know about what is going on with your dad?"*) Then, using the principle of Ask-Tell-Ask discussed in Module I (eighth grade language, frequent checking in, etc), try to fill in any important gaps in the family's knowledge. If the information is bad news, be sure to attend to the family's emotional reaction. (See Module II.)
- 4. Invite a discussion of the current treatment plan:** Let the family know that the goal of this conversation is to discuss the current treatment plan. This allows everyone to be on the same page. (*"I wondered if we could talk about the current treatment plan. As you know things*

*have not been going the way we hoped. We wanted to take this time to step back and re-evaluate how things are going”)*

- 5. Explain the basis for a decision to forgo life-sustaining treatment:** The family may not realize that ICU treatment can be limited or, if they do, they may fail to understand the circumstances in which this would be permissible or appropriate. The physician should explain how potential benefits and burdens are weighed and describe applicable standards for surrogate decision-making with respect to life-sustaining treatment.
  
- 6. Focus the discussion on the preferences, goals, and values of the patient:** To the extent possible, the decision should be focused on the patient’s values. This is true even if the patient cannot participate directly or “in real time.” The intensivist should inquire whether the patient previously expressed preferences about life-sustaining treatment either orally or in writing. (*“Did you ever talk to your dad about his values if he should become sicker?”*) If the patient did not talk about preferences for treatment directly, the intensivist should ask the family to decide with reference to the patient’s goals and values. One might say, for example, *“Let’s try to imagine that [PATIENT] is here with us in this room, listening to this discussion, facing this decision personally. What would [PATIENT] decide?”* Not only is the patient’s preference the most legitimate basis for decision-making, but this approach may also relieve guilt and transcend the potentially conflicting choices of individual family members.

After the family has talked about their loved one’s values, summarize what you have heard. This shows that you have been listening and also will decrease misunderstandings.

- 7. Respond to the Surrogate Reaction:** Conversations about limiting therapy are by their nature upsetting because they make those involved aware of the nearness of death. Emotional reactions are common and are to be expected. They should be acknowledged and responded to before attempting to proceed, since it is usually not possible to continue the conversation in a situation of strong emotion. Also, responding to emotions shows that the clinician cares about the patient and surrogate. This can be as simple as acknowledging that

the conversation is difficult, (*“It’s hard to talk about this, isn’t it?”*), or allowing time for the emotions to lessen.

Elicit surrogates’ reactions to your recommendation and opinion of the plan, and answer their questions. It is not unusual for individuals within the same family to have different perspectives and philosophies about continued use of life-sustaining treatments. Conflict about forgoing such treatments can be particularly destructive and carries the potential for guilt and anger and even permanent family rifts. Thus, while recognizing the ultimate authority of the legal decision-maker, it is useful to engage the entire family in the process and to seek a consensus. One way to do this is to focus on what the patient would have wanted rather than what each of them wants for themselves. (*“I know how hard this is for all of you. I wonder if we can focus on what your dad would say. That is often really hard to do as each of you might want something different. If your dad was sitting here what would he say?”*)

### **Discussing What Happens After a Decision to Forgo Treatment**

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- 1. Talk about the Timing of Forgoing Treatment:** There may be reasons to delay implementation of a decision to forgo treatment—for example, to give an out-of-town family member time to travel to see the patient in a final visit or to allow the family an opportunity to make arrangements for a funeral that according to religious law must occur quickly after death. On the other hand, the family may want the ICU to act immediately on a decision to withdraw life-sustaining treatment, even if the moment is inconvenient for the ICU physician or other staff. In discussing the decision and its implementation, the physician should endeavor to “de-pressurize” the process, explicitly address the issue of timing, and accommodate the family’s schedule, to the greatest extent possible. (*“We have some flexibility about when we withdraw the machines. Do you all have any preferences?”*)

**2. Attend to the family’s social and religious needs. A number of issues often come up as part of the process of forgoing life-sustaining treatment:**

- Ask about whether there are people who would like to say good-bye. (*“Are there any people who you would like to come in and see your dad before we turn off the machines?”*)
- Many families are conflicted about how to talk to children about the patient’s death. Inquiring about whether there are children at home, whether they know about the patient’s illness (*Have you talked to them about what is going on with your Dad?*) and whether they have questions about how to talk to their children (*Do you have any questions about how to talk to the children? Do you want them to come in before we stop the ventilator?*) Your social worker will be able to help you answer questions the family may have about interactions with the children.
- Ask about whether there are any religious or spiritual traditions of which you need to be aware. You cannot know about every religion and what it requires at the end of life. Catholics, for example, may want to receive Sacraments of the Sick prior to death. Therefore, it is important to ask about the patient and family’s needs. (*“Are there any religious or spiritual traditions we should be aware of? Do you want to have a minister come by?”*)
- Ask about their preferences regarding whether they want to be present during the withdrawal of life-sustaining treatment. Families should feel they have the option but not an obligation to be with the patient during or after discontinuation of treatments or at the patient’s time of death. In addition, flexibility about visiting hours should be explicitly offered if possible. It is reassuring for the family to hear that, whether they are present or not, the patient will not be alone but will be attended to at all times by caring ICU professionals.

**3. Describe the Process of Discontinuing Life-Sustaining Treatment:** Families need to understand what will actually take place when treatment is forgone. First ask what the family knows about this. (*“What do you know about turning off breathing machines?”*)

Your explanation should begin with the assurance that the patient's comfort will be maintained, as this is so often the family's primary concern. (*"I want to reassure you that we will keep your sister comfortable throughout this process"*). The intensivist should then describe the procedure as it is performed in that ICU, for example, that the endotracheal tube would be removed, or, if this is not the case in a particular ICU that the tube would remain in place but would be disconnected from the ventilator. If death is the expected outcome, the intensivist should make this clear, while acknowledging that absolute prognostic certainty is unattainable.

The intensivist should talk clearly and simply using words that families can comprehend, rather than the short-hand lingo of ICU rounds—for example, "removing the tube that has been connected to the breathing machine from the patient's mouth" instead of "pulling the tube" or "extubating."

In describing the process, the intensivist should be mindful of the emotional impact of his or her words. The family may feel that their decision, rather than the patient's illness, is the cause of death, or at least that they have failed to fulfill an obligation to "do everything." Thus, the phrases "allow a natural death" or "allow nature to take its course" may be more appropriate and sensitive than "withhold" or "withdraw" or "stop" a treatment. The term "terminal wean" does not belong in a family discussion, it is neither clear nor accurate. After explaining the process, one should ask the family what questions they have.

- 4. Describe What Can Be Expected as the Patient Is Dying:** Most families have no idea what to expect and, in their imaginations, the dying process may be far more frightening than in reality. Start by asking if they have any knowledge about what happens after stopping the machines? Next, because not everyone wants this information, assess their preferences for hearing information about what is likely to happen after discontinuing a therapy. (*"Would you like to hear about what is likely to happen as we turn off XX?"*) A clear and straightforward description of common scenarios can be comforting, especially if coupled with reassurance that patient distress will be treated immediately and aggressively. Such a description might include reference to noise from respiratory secretions, snoring, progressive slowing of heart rate and lowering of blood pressure, twitching, and fast or slow or deep or

shallow breathing. Often, the discontinuation of life-sustaining treatments is accompanied by discontinuation of electronic monitoring; to avoid family distress, this should be explained in advance. (*“We usually turn off the monitors after we remove the breathing machine. We find the beeping and lights are distracting, and we want this to be as peaceful as possible.”*) The family should be reassured that they may stay with the patient after death.

- 5. Summarize and Ask for Questions:** To provide a sense of closure and because information retention is usually poor in highly emotional conversations, the physician should summarize the results of the discussion and establish what will happen next. End by asking what other questions they have (*“What other questions do you have about what happens after we turn off the XX?”*)

## Language That Might Be Helpful

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### 1. To start the conversation

- *“What is your understanding of [Patient’s] current condition?”*
- *“[Patient’s name] has been receiving treatments to sustain his life [such as - the breathing machine, medications to raise his blood pressure to a more normal level, and dialysis because his kidneys have not been working]. Given the current situation, this is an appropriate time for us to talk about whether or not these treatments should be continued.”*

[Or, if the family has raised the issue:]

- *“You have expressed concern that the treatment(s) being given to [Patient] may be causing him to suffer—or, don’t seem to be working—or, may not make sense at this point, given how things have gone – or, no longer seem to be what [Patient] would want if he could decide and for himself today. I am glad you have raised this concern with me.”*

**2. To focus the discussion on the values, goals, and preferences of the patient**

- *“The best way for us to approach this decision is to think about what [Patient] would say if he were here in the room with us today, and knew what we know, and was making the decision for himself.”*
- *“[Patient] is lucky to have family and friends who know him well and care enough about him to speak for him when he can’t speak for himself.”*

**3. To discuss the basis for withholding or withdrawing life-sustaining treatment**

- *“A treatment should not be given if the risks or burdens of giving the treatment are greater than the benefits that the treatment brings to the patient. If a treatment has been started but now no longer brings real benefit, we do not need to continue it—in fact, we must not.”*

**4. To describe the option of withholding or withdrawing life-supporting treatment in clear and sensitive terms**

- *“I want to reassure you that if we remove the breathing tube and the breathing machine and allow [Patient] to breathe on his own, he will be peaceful and comfortable and will not suffer in any way. Although we would not give him any medicines for the purpose of hastening his death, we would give him anything and everything he needs to ensure his comfort at all times.”*
- *“I expect that if we remove the breathing tube and machine, [Patient] will succumb to his illness and die soon. I cannot be certain how long the process of dying will take, but in my judgment it is likely to be minutes to hours rather than days or weeks.”*



## 5. To attend to the family's needs after a decision has been made to forgo treatment.

- *“Are there any other family members you would like to see your dad before we turn off the machines?”*
- *“Are there any spiritual or religious traditions that are important to follow of which we should be aware?”*
- *“Would it be helpful for you to hear about what is likely to happen after we turn off the machine?”*

### Pearls

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1. **Express non-abandonment:** Families may fear consciously or unconsciously that abandonment by the ICU staff will follow a decision to withdraw life-sustaining treatment. Use of phrases like “withdrawal of care” and “nothing more we can do” contributes to this concern and should be avoided. Instead, as an intensivist, you should expressly reassure the family that you will be there with them during this process. The discussion should also emphasize the positive role that the ICU team can play in assuring the patient's comfort and dignity and addressing the family's needs. If death is expected soon after the decision to forgo life-sustaining treatment, and the family feels safe and comfortable in the ICU environment, it is often preferable to continue care in the ICU. In any event, this issue should be addressed in the discussion along with reassurance that care will continue, in whatever venue.
2. **Express support for the family's decision:** Decisions about life-support are invariably weighty and difficult. Whatever decision is made, the family shoulders most of this burden, and doubt, guilt, and sadness are all commonly experienced. In these circumstances, most families welcome the intensivist's support, whereas criticism or open disagreement engender anger and intensify the family's grief. The family and the intensivist may have differing views of the appropriate plan. Still, validation of the family's intentions and their approach to the decision-making can help to lighten the burden that the family carries throughout the patient's illness and after. (*“Respecting your dad's wishes is one of the most difficult things that a family has to do. You are facing a painful loss, I am sure this is very difficult for you.*

*Recognize that in the end, it will be your dad's illness and not your decision per se that leads to death (or whatever results). Still, I know it is hard. I believe that you have thought this through very carefully, and I respect that. [I believe you have made the right decision, the most loving decision.] I want you to know that I will ensure your dad's comfort and help you in every way I can."*)

- 3. Family members may have different needs.** It is important to realize that not all family members want to hear this information. Some people may want more details about the dying process than others. Given there is no way to know what each person wants, the best way to handle these situations is to ask – “A lot of families want to know about what is going to happen after we turn off the machines. Other people find the details too sad or distressing. Would you like me to talk about what you will see?” If some family members want to hear, but others do not, you need to negotiate how you will give the information “It sounds like you want to know this, but your brother really does not want to hear the details. Might I talk to you at the end of the meeting?”

## **Pitfalls**

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- 1. Addressing withdrawal or withholding of life-support with the family without first assessing their understanding of their loved one's medical condition:** Decisions about what should be done in the future depend on one's knowledge of the current medical situation. If the family believes their loved one is getting better, they are unlikely to be willing to discuss forgoing life-sustaining treatment.
- 2. Asking the family to make the medical decisions regarding forgoing life-sustaining treatment:** Asking the family what they want to do is likely to lead to guilt on their part. In addition, it focuses on their goals rather than their loved one's values. It is better to ask family members about the patient's values and then make recommendations about what treatments you believe are most likely to achieve those goals.
- 3. Focusing solely on what you are not going to do:** Family members worry about doing enough for the loved one. Focusing on limiting life-sustaining treatment may make them feel like they are being abandoned or they are abandoning. Therefore it is better to spend as

much time on what are you doing to achieve the patient's values as on what is not going to be done.

4. **Expressing frustration with a family that makes a thoughtful choice about life-sustaining treatments that diverges from your recommendation:** A family may feel obligated by religious or other beliefs to make a certain decision; they are doing the best they can. Your disapproval is likely only to exacerbate conflict and impede future decision-making.
  
5. **Feeling that after the family decides to forgo life-sustaining treatment that your job is done:** Maintenance of patient comfort during withdrawal or withholding of life-sustaining treatment will generally require a commitment of physician and nurse time. Remember that families often fear on some level that a decision to withdraw life-sustaining treatment will lead to abandonment by the ICU. The ICU team can play a positive role in assuring the patient's comfort and dignity and addressing the family's needs. The intensivist should be aware of the importance of ICU support during this process and expressly reassure the family that they will not be abandoned (*"We will walk you through this;" "I will come back and check on you;" "We will be there and make sure your loved one does not suffer"*).

The table on the following pages outlines steps and recommendations for talking about forgoing life-sustaining treatment with a family.

## CRITICAL CARE COMMUNICATION (C3)

<b>TALKING ABOUT FORGOING LIFE-SUSTAINING TREATMENT*</b>	
<b>1. Establish the setting</b>	
Make sure the right people are there.	<ul style="list-style-type: none"> <li>• Patient’s or surrogate’s loved ones</li> <li>• Staff</li> </ul>
Find a comfortable, quiet location.	<ul style="list-style-type: none"> <li>• Places for everyone to sit; tissues</li> <li>• Secluded from others</li> <li>• Everyone able to see and hear each other</li> </ul>
Introduce everyone at the beginning.	<ul style="list-style-type: none"> <li>• <i>“Could we start by introducing everyone?”</i></li> <li>• <i>“How are you related to Ms. Jones?”</i></li> </ul>
Introduce the topic for discussion.	<ul style="list-style-type: none"> <li>• <i>“I was hoping we could talk about the next steps in your/your loved one’s care.”</i></li> </ul>
<b>2. Review the patient’s situation</b>	
Elicit surrogate understanding.	<ul style="list-style-type: none"> <li>• <i>“Can you tell me your understanding of what is going on with your medical situation?”</i></li> <li>• <i>“What have the other doctors or others told you about your dad’s medical situation?”</i></li> </ul>
Educate as needed.	<ul style="list-style-type: none"> <li>• <i>“That’s right, his lungs are not working. What that means is I do not think he is likely to ever come off the ventilator.”</i></li> </ul>
<b>3. Review overall goals of care</b>	
Invite a discussion of the treatment goals.	<ul style="list-style-type: none"> <li>• <i>“I wondered if we could talk about the current treatment plan. As you know things have not been going the way we hoped. We wanted to take this time to step back and re-evaluate how things are going.”</i></li> </ul>
Elicit from surrogate.	<ul style="list-style-type: none"> <li>• <i>“If your dad was sitting here and could hear what we have been saying what do you think he would say?”</i></li> </ul>
Summarize to confirm.	<ul style="list-style-type: none"> <li>• <i>“So it sounds like the most important thing is to make sure your father is comfortable.”</i></li> </ul>
<b>4. Relate your recommendation for withholding or withdrawing treatment</b>	
State your recommendation.	<ul style="list-style-type: none"> <li>• <i>“I recommend that we focus on keeping your dad comfortable and not do any more of these treatments that only prolong his suffering.”</i></li> </ul>
Describe how you feel your plan is consistent with the patient’ overall goals.	<ul style="list-style-type: none"> <li>• <i>“The reason I think this is the best plan is that your dad never wanted to be kept alive if he thought he could not go back home and at least be able to talk to you and walk around.”</i></li> </ul>

## TALKING ABOUT FORGOING LIFE-SUSTAINING TREATMENT\*

Describe what treatments will be provided and what will not be done, such as....	<ul style="list-style-type: none"> <li>• <i>“We will use medicines to improve his breathing and comfort.”</i></li> </ul>
<b>5. Respond to patient or surrogate reaction</b>	
Attend to emotions.	<ul style="list-style-type: none"> <li>• <i>“It’s hard getting to this point isn’t it?”</i></li> </ul>
Is recommendation consistent with patient’s values, goals?	<ul style="list-style-type: none"> <li>• <i>“Does that sound like what your Mom would have wanted?”</i></li> </ul>
Answer questions.	<ul style="list-style-type: none"> <li>• <i>“I’ll be around if you think of things you want to ask me later, but are there questions can I answer now?”</i></li> </ul>
<b>6. What happens after a decision to forgo a treatment</b>	
Talk about the timing.	<ul style="list-style-type: none"> <li>• <i>“Do you have any preferences about when we turn off the machines?”</i></li> </ul>
Attend to the family’s religious and social needs.	<ul style="list-style-type: none"> <li>• <i>“Are there any other people who would like to come in and see your Dad?”</i></li> <li>• <i>“Are there any religious or spiritual traditions that you would like us to be aware of?”</i></li> </ul>
Describe the process of discontinuing a treatment.	<ul style="list-style-type: none"> <li>• <i>“After you all have said your good-byes, we will take out the tube in your brother’s mouth. Before we do that we will give him some medicine to make sure he stays comfortable. In addition, we will be there to make sure that after the tube is out, he stays comfortable. If he looks short of breath or uncomfortable we will give him some medicine. What questions do you have about this?”</i></li> </ul>
Ask if they want to hear what will happen after discontinuing the treatment.	<ul style="list-style-type: none"> <li>• <i>“Would you like to hear about what is likely to happen to your loved one [name] after we discontinue the ventilator?”</i></li> </ul>
Describe the dying process.	<ul style="list-style-type: none"> <li>• <i>“Sometimes during the process, people make gurgling noises. I want to reassure you that these do not mean the patient is suffering. The noises are due to secretions in the back of the mouth and throat. I view them like snoring. They make other people uncomfortable but do not bother the patient. If these happen, we will try a medicine under the tongue. We may also sit your Dad up or roll him over as that may make them go away.”</i></li> </ul>
<b>7. Summary and Follow-Up</b>	
Ask for questions.	<ul style="list-style-type: none"> <li>• <i>“Do you have any questions about what we spoke about?”</i></li> </ul>

\*Modified from Evans WG, Hunt SC, Chaitin E, Arnold RM. Withholding and withdrawing life-sustaining therapies. In Emanuel L, Librach SL (eds) Palliative Care: Core skills and competencies. Saunders Elsevier. New York. 2007: 249-266.

## CRITICAL CARE COMMUNICATION (C3)

### MODULE VII: NAVIGATING CONFLICT WITH FAMILIES

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*These learning modules for intensivists have been developed based on the success of communications skills modules for oncologists, which are available through Oncotalk at <http://depts.washington.edu/oncotalk/learn/modules.html>*

In this module the term ‘family’ is used to refer to all the people who are emotionally intimate or biologically connected to the patient. Thus a patient’s ‘family,’ for our purposes, may include an unmarried partner, a close friend, and/or a second cousin—in addition to a spouse, children, or parents.

#### Learning Objectives

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After reading this module, participants should be able to do the following:

1. Generate a differential diagnosis for why families (and some patients) may choose intensive care therapies that you believe offer no reasonable hope of medical benefit.
2. Recognize that conversations with families around limiting life support are less about prognosis than about meaning.
3. Be aware of family members’ burden of responsibility and potential guilt in making decisions to limit life support.
4. Respond empathically to family members’ hopes for recovery, including hoped-for miracles, without compromising the integrity of medical decision making.
5. Be more aware of the personal and cultural biases that you bring to conversations with families around limiting life support.

#### Why This Topic?

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Patients admitted to intensive care units (ICUs) are at high risk of dying. Mortality rates vary from approximately 5% in some surgical ICUs to as high as 45% in medical ICUs, which serve a high proportion of patients with underlying malignancies. Of patients who die in intensive care, the majority die following a considered decision to withhold or withdraw life-sustaining therapies. Thus, over the past 10-15 years, handling conversations around limiting life support has become a core competency for critical care practitioners (intensivists).

Clinical research suggests that most conversations around limiting life support are not contentious. These conversations are inevitably emotionally charged and may be sad or even tragic, but in the majority of cases, families and physicians come together around the decision without significant disagreement. However, the nature of critical care practice—time-sensitive decisions regarding life or death made under conditions of uncertainty—leads to significant disagreement about limiting or continuing life support in a minority of cases.

Breen et al. (*See Readings and Resources List.*) examined conflict associated with decisions to limit life-sustaining treatment in six ICUs at an academic medical center and found that at least one clinician described a conflict in 78% of 102 consecutive cases. Clinician-family conflicts were identified in 48% of cases, and clinician-clinician conflicts in 48% of cases. Stoddard (*See Readings and Resources List.*) examined conflicts in seven medical and surgical ICUs and identified conflicts involving 32% of patients with long stays (defined as >85<sup>th</sup> percentile for that unit). An informal poll of physician executives indicated that this group spent “at least 20% of their time” dealing with conflict.

The challenge in critical care communication is to manage disagreements and promote sound decision-making while decreasing the animosity that can come with conflict. This module is an attempt to sketch an intellectual framework for developing clinical skills in this area.

Two important insights will facilitate successful communications in the ICU. First, recognize that disagreement is a natural and expected part of conversations with families about life support. If disagreement is seen as part of the landscape of critical care, then it becomes easier to approach families who disagree with physician recommendations in a spirit of curiosity and inquiry, rather than reacting defensively. Second, understand that conversations about limiting life support are not primarily about information but about meaning. Too often we think the conversation is about facts which we know and the family does not know. If this were true, all we would need to do is to provide information in a way that the family can understand. Rather than being about facts, conflict is often about the story that one tells about the “facts.” While the doctor may see the situation as a futile one in which the patient is going to die, the family may

see the situation as one that is testing their faith and requires them to have faith in a miracle. Similarly we view our role as prolonging quality life; while families may view the situation as one that requires that they do not “give up.”

This runs counter to so much medical training that it is worth repeating: *Discussions about withholding and withdrawing life support are not fundamentally discussions about prognosis. They are discussions about the meaning attached to different strategies of support or withdrawal of support, in the context of the patient's life, framed by a family and colored by their interactions with physicians and other health care providers.*

### **Eliciting and Responding to the Family's Perspective**

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Although some doctors want to deal with conflicts in the ICU by appealing to futility, we think it should be used sparingly. Appealing to futility assumes that the doctors have the “correct” knowledge about the medical facts. Given this knowledge, doctors should be able to unilaterally say, as professionals, what should and should not be done. While it is unarguable that some strategies in some patients appear to have no reasonable chance of success, appealing to futility will not help in the large majority of cases.

In most cases, the conflict centers on one of two issues. The first situation involves high-intensity care that has a low but non-zero probability of success. In this case, the doctor and family may disagree about the usefulness of continuing treatment when there is a low probability of success. For example, one empirical study using hypothetical scenarios found that 32% of surrogates elected to continue life support with a < 1% survival estimate, and 18% of surrogates elected to continue treatment when the physician believed that the patient had no chance of survival. Interesting doubt about physicians' prognostic ability based either on uncertainty, previous experience or the need to see for themselves underlies much of the disagreement.

The second situation involves differing assessments about the appropriate goals of medicine. For example, the doctor may think that ICU care is not appropriate if the outcome is prolonged survival for a demented patient, while the family may believe that keeping their loved one alive is worthwhile even if they are cognitively limited. The downside of appealing to futility early is



that when physicians do so they run the risk of giving the family the impression that the medical team does not want to do everything possible for the patient. This can diminish family trust and create a vicious cycle of increasing futility and diminishing trust that leaves both sides feeling badly.

We recognize that the medical profession in its social context needs to take a primary role in establishing limits on medical interventions. We also feel strongly, however, that futility is not a successful bedside negotiating strategy because it misunderstands the nature of disagreements around decisions to limit life support and imposes a solution based on power (the right to make a decision unilaterally) rather than on discussion. In our experience, most disagreements, including disagreements about so-called "futile" care, can be resolved with good communication skills applied over time. The key is to understand the family members' thinking (why is this caring family making a decision that I disagree with), to respond to their emotions, and to see if you can find areas of mutual agreement.

### **Recommended Procedure**

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#### **1. Cognitive preparatory work prior to the conversation – understand the social and legal climate for (surrogate) decision-makers in your region:**

- a. Patient's stated preference or durable power of attorney for healthcare.
- b. Statutory or common law hierarchy in your state or region.
- c. Who is most likely to know what the patient would have wanted (substituted judgment)?
- d. Who is best able to represent the patient's interests (best interest standard)?
- e. Does the surrogate decision-maker have the ability to make health care decisions?

#### **2. Explore family perceptions of the clinical situation and medical care options:**

***THIS IS CRUCIAL AND SHOULD BE YOUR FIRST STEP WHEN THERE IS A CONFLICT.*** (“Tell me what others have told you is going on with your loved one? What is your understanding of what is going on with your loved one? What have other doctors said?”)

- a. Misunderstanding may be the cause for disagreement and/or conflict. The following possibilities are not mutually exclusive and may exist in combination:
- ***The family has not been told anything about the situation.*** In this case, start by asking them what they know and build on that to give the family accurate information at a level they can understand.
  - ***The family has been given information, but in language they did not understand.*** In this case, start again, using their understanding as a starting point, adjusting your language as required, and checking frequently for comprehension using questions. It may help to draw pictures or use other visual aids.
  - ***The family has been given conflicting information by different healthcare providers.*** In many cases, the multidisciplinary intensive care team includes nurses, respiratory therapist, social workers, and physicians at multiple levels, all of whom may interact with the family and provide different information. If this is the case, explain the discrepancies, and try to create a unifying picture for the family.
  - ***The family is receiving mixed messages.*** The family was previously given encouraging or hopeful information and may continue to be supported in their optimism by health care providers who “don’t want to take away all hope.” Understand that almost all families want honesty and clarity about the medical facts, and that the challenge lies with the medical provider who must provide disappointing, sad, and even tragic news. Explain what has been done and why things have changed. Explore with the family things they may hope for that do not involve patient recovery: comfort, dignity, a peaceful death.
  - ***The family is obtaining information from multiple sources.*** Families triangulate information from multiple sources – from the internet, from friends, from strangers in the waiting room. Take the time to learn what they are thinking and what others have been telling them.
  - ***What the family is seeing conflicts with what you are saying.*** What we say may not fit with what families see. What we see as random eye movements may be interpreted as purposeful movements when they occur as the family walk into the room. It may be hard to believe a patient is dead when they “look alive”. In these

cases, it may help to provide other empirical information that the family can see to help them understand what is going on – X-rays for example.

If any of the factors noted above are present it may also help to:

- Ask the family if you can share your understanding of what is going on with the patient?
- Try to build your description on what the family does understand (“*As you said your loved one’s kidneys do not work. That is because of the very bad infection.*”)
- Use eighth-grade language without jargon.
- Provide no more than three pieces of information without checking in to assess understanding. (“*What questions do you have about that?*”)
- Give general information about what is happening and what is likely to happen; do not focus on the biological details. The family can ask about these. (“*Your loved one’s had a large stroke and that is why she is not responding. Unfortunately, she is not likely to wake up.*”)
- Acknowledge their understanding of the situation and build on it to expand their knowledge base.
- Write things down.

### **3. Attend to the family’s emotions.**

- ***The family is likely under stress.*** Sleep deprivation, internal conflicts, long-standing guilt all impede understanding of the information they have been given and interferes with decision-making.
- ***The family might be in denial.*** Denial is a psychological defense mechanism to protect an individual or group from hearing news that could be psychologically harmful. In this case, be respectful, curious, and try to understand the emotions underlying the news that triggers this defense mechanism. Recognize that arguing with a person/family in denial is not likely to change their mind since it is a psychological mechanism and not a considered assessment of the facts; it risks convincing the person/family that you do not understand and are not on their side.

- ***The family is probably sad and grieving.*** The normal reaction to bad news is to have strong emotions. Sadness is very common. When people are experiencing strong emotions, it may be hard for them to make decisions as the emotions flood their cognitive abilities.
- ***The family could be frustrated or angry.*** Another normal reaction to bad news is anger and frustration. Although it often feels like they are mad at you, more commonly the anger is the family's way to express their sadness over the patient's illness.

***Ways to deal with emotions:***

- First, be aware of the importance of emotions in conflicts. It is easy to get overwhelmed with all of the factual information in the ICU. However, most studies show that families' experience and decision-making processes are very influenced by their emotions. One way to get better at recognizing the family's emotion is to pay attention to what you are feeling. If you are sad, for example, that may be because there is a great deal of sadness in the room. Another way to recognize that emotions may be at play is when the family seems to be asking the same question (or talking about the same thing over and over). If the factual response does not work, turn to emotions.
- Second, NURSE the emotions. (*See Module I.*) By letting the family know you are trying to understand what they are going through, you will help them gain more control over their emotions.
- Prior to going back to factual matters, ask permission to make sure the family member(s) can "change gears." ("*Would it be okay, if we talked about what comes next?*")

**4. Address common patterns of conflict between the family and the health care team:**

The following possibilities are not mutually exclusive and may exist in combination:

- ***The family is acting out of guilt or fear of being responsible for a decision that will shorten the life of the patient.*** In this case, begin by trying to understand the emotions that underlie the feelings of guilt. Clarify the family's role in the decision-

making process. Specifically, make it clear that they are not the decision maker but rather the conduit to the patient's wishes that allows the medical team to make the best decision for the patient. (*“It would help us take better care of your loved one, if you could tell us more about his/her values.”* OR *“If your loved one was sitting here, what would (s)he say?”*) Emphasize that setting limits to life support is a community decision founded on respect for the patient's wishes. Avoid the cultural taboo of “giving up” on a patient, and reframe discussions in terms of “letting a loved one go.” (*“We are not asking you to make this decision. Your role is to help us understand what your loved one would have wanted so, as the doctors, we can make recommendations to you.”*)

- ***The family does not trust the health care team.*** This may be for many reasons including past experience with the health care profession, the communication style of individual health care providers, cultural and/or religious factors. If trust is lacking, work to build it: explain to the family *the things that you are doing* for the patient. Emphasize that you are hoping for improvement. Acknowledge the lack of trust and ask the family what you can do to improve the relationship between the health care team and the family. Take advantage of other healthcare providers or members of the multidisciplinary team, if appropriate, such as social work, chaplaincy, and palliative care consultation.
- ***The family is hoping for a miracle.*** This is one of the most difficult issues to negotiate. Miracles are by definition unpredictable, but they should not immediately be regarded as irrational, since there is much that we do not understand. First there are some things that you should not do. It does not help to tell the family how sick the patient is or how unlikely it is that the patient will get better. (*By definition, if the family is hoping for a miracle they know this!*) Second, often miracles are associated with strong emotions— fear, worry—and one should be sure to empathize with the family’s situation. (*“I see how important a miracle is to you.”*) Third, it is all right to say that you hope a miracle occurs. After all, given miracles are supernatural and out of our control, it would be wonderful. Moreover, this may help the family to see you are on their side. (*“A miracle would be wonderful.”*)

Start by asking the family how they understand miracles. If possible, broaden the conversation by asking about other things the family can hope for besides a miraculous cure. (“*Are there any other things you are hoping for?*”) See if they are able to talk about what it would mean to them if a miracle did not happen. One way to do this is to see if they can ***hope for the best and yet prepare for the worst.*** (“*I know how much you want a miracle. I wonder if you can think about this not happening.*” OR “*I see how much you want a miracle. I wonder if we can talk about what we should do if this does not happen.*”) If trust in a miracle is rooted in a religious tradition, try to involve a religious leader from that tradition, if possible. The theological insight that religious and pastoral experts bring to the bedside is that religious faith generally means accepting the unwanted outcome as reflecting God's wishes, rather than believing that one is in a position to dictate to God what the appropriate outcome should be. This is not typically a conversation that medical professionals can or should have at the bedside, but a priest, minister, rabbi, or imam may be very helpful.

**5. Consider ineffective or dysfunctional communication by health care providers as a primary cause of the family’s misunderstanding.**

- ***Attend to your own responses to the family.*** Be clear, honest, and insightful about your own response both to the patient’s care and to the family’s involvement. Do you like them and find them engaging? Do they annoy you and disrupt your work habits? If the latter, how can you keep your personal feelings from affecting your judgment?
- ***How do poor patient outcomes affect you?*** How does death affect you? Do you find that you offer more therapy because you don’t want the family to be too upset? Do you have trouble giving bad news when you know the family will be sad? Do you regularly debrief with colleague, friend, loved one, or counselor?
- ***Calibrate your own practice style.*** Try to become clear in your own mind about the range of medically reasonable care in a given situation. Does this family’s view of what the patient would have wanted conflict with your understanding of the goals of medicine? Is there a reason why this family is getting to you? You may have conceptualized your role as promoting quality life for patients, and the patient may

have different values. Can you think about your role in this case in a way that does not violate your values (i.e., helping the patient die in a way consistent with her values)? In these situations, it is often helpful to solicit opinions from more senior colleagues. It may be helpful to speak with members of an ethics committee or palliative care service to serve as an additional check on your own views.

- ***Is a dispute over life support a power struggle, a matter of resource allocation or an issue of conscience?*** Do differences about goals of care reach the level of conscience so that you can no longer care for the patient?
- ***Be aware that physicians have issues too.*** Clinical research estimates that between one-third and one-half of conflicts around limiting life support involve physicians who continue to pursue aggressive treatment strategies when the family and other providers believe that such a plan of care is no longer appropriate. Obviously, this presents a significant challenge to the critical care fellow when the attending intensivist is pursuing a high-intensity strategy with a low likelihood of benefit.
- ***Consider that the health care team's internal disagreements may be contributing to the problem.*** If different health care providers have different views about what should be done and are communicating these to the family, it is understandable that the family would be in disagreement. In these cases, it is critical to get the team on the same page, devising an approach that the entire team can commit to using consistently.

**6. Identify the relevant issues above, and devise a strategy that will address those issues. Review this with the family or surrogate decision maker. Some options include the following:**

- ***Give them time.*** Particularly if this is the first time they have heard the bad news, it may take some time for them to process. Allowing them a day or two to reflect and come to grips with the bad news may help.
- ***Consider a time-limited trial with clear goals.*** (See Module III.)
- ***Compromise.*** While you may think it is time to focus on comfort only, the family may be too sad to think about not doing “*everything for their loved one.*” One option

is again to “*to hope for the best and plan for the worst.*” They may think it is reasonable if things “do not go well” to increase the intensity level of care.

- ***Follow the family’s wishes.*** In some cases, after discussion with the family, it is clear that they are well-informed and doing the best they can to act as responsible surrogates for the patient. The problem may be that the patient’s values are different than yours. The patient may believe that any life, regardless of quality, is worth living while you may think that being in a coma is not “living.” Or the patient may be willing to undergo low probability treatments that you feel are very unlikely to bring about much medical benefit. In these situations, the health care team and patient have a true value conflict that may not be resolvable by negotiation.
- ***Institute a ‘harm reduction’ strategy.*** If the family clearly states their loved one’s philosophy of “wanting even minimally helpful therapies” further negotiation is unlikely to be productive. ***Instead we would urge the adoption of the*** following “harm reduction” strategy. The goal is to respect the patient’s/family’s wishes while at the same time decreasing staff moral distress and promoting good symptom management. It would consist of the following steps
  - **Acknowledge the patient’s family’s values and philosophy so that the family feels heard and respected.** Document the decision and reasoning in the chart
  - **Stop regularly discussing preferences about invasive treatments** unless raised by the family, or unless there is a significant deterioration in the patient’s condition. Try to develop shared additional goals such as promoting comfort and trying to reverse correctable medical problems.
  - **Address the medical team’s discomfort, disapproval, or distress** about the prospect of having to provide CPR when they think it will not work by:
    - Communicating the reasoning behind the full CPR decision with others on the treatment team.
    - Finding other patient-centered goals that the health care team can feel good about working toward, such as better symptom management, or supporting the family. This requires that teams, despite the disagreement over ‘doing everything’, spend



even more time with the family finding common ground (“*In addition to hoping his health gets better, what else are you hoping for?*”) This goes against many clinicians’ normal inclination to withdraw from family/patient if one can not convince them to forgo ‘everything’. The problem with avoiding encounters is that the family is likely to view this as abandonment and assume that you do not care. In reaction, they may request even more treatment as they try to ensure that the clinicians pay attention to them and remain engaged.

In these circumstances, clinicians can still exercise clinical judgment. This means not offering therapies for which there is no data supporting their use and by setting a limit on its use if it is not achieving the patient-defined goal. We realize that it is sometimes hard, particularly in the Intensive Care Unit, to define ineffectual care if the only goal is prolonged existence. How can one be sure that a third vasopressor will not, at least briefly, help a patient who is hypotensive on two drugs. There is no simple answer to this question: requiring that it is logically impossible that the treatment might help is too high a standard, requiring randomized controlled data is too low. The decision requires clinical judgment, preferably by a team of experienced clinicians who reflect the current consensus about the treatment’s effectiveness.

Take CPR as an example. Although there is no clear empirical evidence to guide physicians in determining when to stop CPR, in extreme cases where the odds of responding to CPR are extremely poor at the outset, one can argue in favor of stopping after one complete cycle of CPR if the patient shows no immediate signs of response. This is very different from a “show code” or a “slow code” for there is a genuine, albeit brief, attempt at CPR for one cycle before stopping. This allows the patient and family to know that “everything possible” was done, but avoids having staff go through the ordeal of prolonged CPR with no prospect of recovery.

## **7. Consider an ethics or palliative care consultation.**

### **Pearls**

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Ideas to facilitate conversations about what you consider to be medically inappropriate treatments:

1. ***Be rigorously honest about the limits of your own ability to predict the future.*** What is the likelihood that you are wrong, and your patient will get better despite your expectations? Are you willing to bet their life that you're right?
2. ***Always ask whether a dispute about limiting life support is about resource allocation, the goals of medicine, or a power struggle about who gets to decide, rather than an issue of prognostication.***
3. Do you believe that your interests are in providing the best possible care for the patient? If so, ***make the assumption that the family's intentions are also to provide the best care for the patient.*** Be curious and inquisitive. Ask yourself: "How is it that they could believe [X] when I think that it is inappropriate?"
4. ***Emphasize that you hope the patient will improve, even if your medical judgment is that such improvement is extremely unlikely.*** It is important to demonstrate care and concern about the patient to the family in order to show that you are "on their side." Facilitating trust is an important step toward avoiding and/or diffusing conflict.
5. ***Ask if there is anything you can do to help the family.*** You might consider saying, "*One of my goals is to ensure that, six months from now, you will look back and say that regardless of what happens, you made the best decision you could.*"

## **Pitfalls**

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1. ***Don't try to convince the family that their decision is unreasonable.*** It is wiser to try to understand the family's decision rather than to try to change their mind. The process of explaining their thinking to someone they trust who seems genuinely interested in their thoughts may itself change their mind.
2. ***Don't ask the family what they want to do.*** Framing a discussion about limiting life support as the family's decision may complicate decision making and increase survivor guilt. Such framing also misunderstands the ethical principle that a surrogate should try to do what the patient would have wanted, not make a decision for him or herself.
3. ***Don't deal with decisions on a purely informational level*** without attending to the role of emotion in decisions.

## Phrases That Might Be Helpful:

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### 1. In evaluating misunderstanding:

- *"Tell me what others are telling you about what is going on with your dad?"*
- *"I want to make sure that we are on the same page. Can you please take a minute to tell me what you understand is going on with your dad."*

### 2. Attending to the family's emotions (NURSE mnemonic, Module I):

- Name the emotion. *"I know this is not what you wanted to hear. It must be overwhelming."*
- Understand the emotion. *"I can see how difficult this is for you."*
- Respect the participants. *"Given all that has happened, I respect how hard you're trying to do what your dad would have wanted."*
- Support the participants. *"I will come back tomorrow. I'm sure you have questions, so please write them down so that we can go over each one of them."*
- Explore possibilities. *"Tell me a little more about what you are thinking."*

### 3. Dealing with denial

- *"I can sense how much you were hoping for good news."*
- *"I wish things would have worked out differently."*
- *"This must be devastating for you."*

### 4. Dealing with guilt

- *"I am not asking you to make a medical decision. I would never ask you as a family member to make a decision like this for your loved one. I want you to help me understand what your dad would have said if he were sitting here and could understand what we have been talking about."*
- *"I can see how hard this is for you. I respect that you're trying to follow your dad's wishes even though you would want something different for yourself."*
- *"I would never ask a family to give up on a patient or loved one. Sometimes, however, love and respect require that we let someone go."*

## 5. Dealing with miracles

- *"Can you tell me more about what a miracle would look like for you?"*

### **Addendum: A Case-based Primer of Medical Negotiation**

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In a medical context, negotiation requires the parties to respect divergent opinions, to avoid the very similar power-based strategies of autonomy and futility, and to work together towards consensus. Underlying the negotiation model is a specific conception of the relationship between physician and patient. Under a model of paternalism, the physician is assumed to know the best answer for the patient and to act on that knowledge. Under a model of autonomy and informed consent, the physician is assumed to have access to the correct information which (s)he provides to the patient and family. Under a negotiation model, the physician accepts the patient as an equal partner in a discussion in which the physician has a fiduciary interest in the patient's decision. When we say they are equal partners, of course, this does not mean that they have equal information. They do not. They are equal in that each brings to the discussion something essential. The physician brings his or her knowledge, experience, and genuine interest in the patient's welfare; the patient brings his or her set of values and goals, need to know, and willingness to accept uncertainty and risk. These are the raw materials of decision-making in a negotiation model, which does not assume that either party can make the correct decision without the input of the other.

Medical education does not train physicians to be effective negotiators in this sense. We spend a great deal of time practicing communications skills, but that time tends to be focused around presenting information succinctly, clearly, and effectively. Decision-making is modeled as an evidence-based weighing of information in order to arrive at the correct diagnosis or treatment or, at least, the best answer available under conditions of uncertainty. Although communication between two people has informational aspects and emotional aspects, medical education systematically emphasizes informational content over emotional content. Furthermore, medical training conditions one to dissociate emotional responses from cognitive assessments. In some contexts, particularly in emergency situations, it may be important to effectively practice to respond automatically. However, it is one thing to be aware of and to block out emotional responses that threaten good clinical decision-making and quite another to ignore those responses

altogether. If physicians have a tendency to emphasize information in communications and a predisposition to block the emotional side of interpersonal interactions, then they risk entering into family conversations with a bias that these interactions are about truth in some objective sense, and not about perceptions, emotions, and the interplay of communication.

How can we work our way out of this? Mediation, negotiation, and conflict resolution are areas of active research in business, law, and schools of international relations around the country. The model below comes from outside a medical context. It is the model of *Principled Negotiation* developed at Harvard Law School and popularized in a series of books by Roger Fisher and colleagues. The best-known of these is Getting to Yes. Fisher and colleagues identify the following four simple principles for effective principled negotiation:

1. Separate the people from the problem.
2. Focus on interests, not positions.
3. Invent options for mutual gain.
4. Insist on using objective criteria.

To make it clearer how these principles apply to the medical context, we will describe and simultaneously walk through a recent case of conflict from the ICU:

The patient was a 92-year-old woman admitted for elective surgical repair of an enlarging AAA. Three days postoperatively, she developed atrial fibrillation and hypotension. Her ventricular rate was ultimately controlled, and she converted to sinus rhythm, but not before the hypotension caused hypoxic-ischemic encephalopathy and an ischemic insult to her kidneys resulting in complete renal failure. She was heavily sedated for “agitation,” and intubated for respiratory support. She did not wean due to cognitive impairment and baseline COPD and on postoperative day 12, the surgical service performed a tracheotomy. On post operative day 50, a new attending intensivist (Dr. P) came on service to assume care of the patient. At that point, the patient remained ventilator and dialysis dependent and had only a withdrawal response to pain. Dr. P was told that there was no advance directive and the daughter was “very difficult” and that both

nursing and medical staff had been completely cut off in any discussion of limiting life-sustaining therapies.

The first of Fisher and colleagues' principles is to *separate the people from the problem*. This is the opposite of the natural tendency of many physicians, as it is natural to many patients and families to personify problems with their physician. How often have you heard a physician referred to as impossible to talk to, or a family member described as someone you can't deal with? Those accusations may be true, but more often they reflect disagreements on the issues. We need to remind ourselves that when you interact with people, you interact with perceptions (theirs and yours), emotions (theirs and yours), and with all the inherent difficulties of communications such as transference, counter-transference, inattention, the tendency to talk at someone and not to them, as well as the misunderstandings that can arise when technical language is interpreted in a non-technical context.

The first step in analyzing this situation is to separate the surrogate decision-maker from the problem. To do so, it is essential to define the problem clearly: the patient is elderly. She had poor functional status preoperatively and now has been in the ICU for seven weeks, where she remains ventilator and dialysis dependent. She is unlikely to recover cognitive function, and we do not know what her wishes for care would have been in this circumstance.

We need to do more than to identify the surrogate decision-maker, we must attempt to see the interaction from her point of view, to understand how emotions enter into and affect decision-making. That is to say we need to understand the family's perception of the problem. The patient was widowed. She had three children, two of whom lived on the opposite coast. The daughter who lived locally was her mother's primary caregiver and looked after her very conscientiously. The daughter says the patient initially had not wanted to have AAA surgery, but when she heard more about the risks of the AAA, she persuaded the patient to go ahead with the surgery. After all the post-op complications, the daughter worried whether she had done the right thing and felt that her only option was to continue treatments in hope she would get better. Given they had decided to have the surgery, she could not imagine stopping. In talking to her, it was clear that she felt responsible, guilty and doubted her judgment.

That was the surrogate decision-maker coming to the discussion. She was not a “difficult” person, only a loving daughter troubled by her mother’s illness and her own role in it.

The second of Fisher’s principles is to *focus on interests and to avoid staking out positions*. This sounds easier than it is. Physicians are taught to identify the correct answer, that is, to find a right way to do things. If we’ve made a considered decision that, on reflection, we believe to be correct, then the tendency when faced with disagreement is to focus on the factual basis for our conclusion and to ignore the interests that may lead someone to arrive at a different position. We may wind up arguing over positions—in this case, the daughter’s position that her mother should continue to be treated in the ICU, and the ICU staff’s position that continued critical care was no longer appropriate—with the resultant stalemate (i.e., she’d been in the ICU for more than seven weeks with essentially no clinical change for the past five weeks.) Why was there no movement? Each party had staked out its position, and there seemed no easy way to bridge the gap.

How can we identify interests? *Don’t guess, ask. Specifically, ask why someone holds the position that they do, not to demand justification but to understand the needs, hopes and fears that the position serves for them.* What were the interests here? The intensivist has both practical and theoretical interests. Practically, the patient is occupying a scarce resource but is not going to improve to her prior baseline and, from an administrative perspective, her presence in the ICU is leading to bickering and morale problems among the staff who feel that her continued treatment is inappropriate. Just as important, the intensivist has an ethical interest, namely, a clear responsibility to make sure that the treatment the patient is receiving is in accordance with her wishes. In addition, the doctor may feel that continued treatment violates her ethical obligation to only provide evidence-based care. Finally the intensivist has an emotional interest. She may feel angry that she is spending her time on care that she thinks is “futile” and frustrated that the daughter does not “get it.”

What are the daughter’s interests in continuing medical therapy? She was confident that her mother was receiving excellent care. However, the daughter was uncertain how much cognitive function the patient would recover. She was concerned about criticism that she might receive from her brother and sister (who left decisions about their mother’s care to her) about a decision to limit their mother’s life support. She questioned her own judgment since she had gotten her

mother into this mess in the first place. Finally, her emotional interests are fear and sadness over her mother's illness. In addition, she feels guilty over her role in the decision-making process. Once these interests are identified, the stalemate becomes a very different discussion. Our job as health care providers is to attend both to the emotional and cognitive interests:

- ***Excellent care*** -> We will reassure her that the patient will continue to receive excellent care.
- ***Uncertainty over recovery of function*** -> We will act to reduce uncertainty by reconsulting services that may be able to help define specific prognostic questions.
- ***Criticism from family*** -> We will acknowledge how difficult it is to be carrying the burden of the decision alone, and we will shift that burden in two ways. First, we will make it absolutely clear that the person guiding us in what to do is the patient herself. If we elect to discontinue life support, we do so not because we've grown weary ("given up") but because we respect the patient's wishes ("letting go"). Second, as physicians, we avoid the Chinese menu approach to informed consent (i.e., "*here's the data, make up your mind, it's not my decision.*") We have an interest in the decision, namely, that it be bearable for the surrogate decision maker, maintain the integrity of the family unit, and respect the patient's wishes. If we need to talk with the siblings, fine. We are involved, not detached.
- ***Question her judgment*** -> We will reassure the daughter that both the patient and the surgeon agreed with the decision to proceed to surgery, and we work to have the surgeon reinforce that message.

Once you have identified the concerns underlying the choices people make, you can seek creative ways to meet those concerns, or in Fisher's language, to *invent options for mutual gain*. The most common interim measure is to establish a time-limited trial of some therapy, dialysis, mechanical ventilation, antibiotic therapy. In this case, therapy had been continued, but there had been no attempt to establish an outcome or point at which therapy would be reassessed. We explored several possibilities for placement in chronic care facilities, but there was none available within 100 miles that would accept a patient on a ventilator who required hemodialysis. This might represent another impasse: we couldn't place the patient, and we did not believe that continued ICU care was appropriate, but the daughter insisted on continuing intensive care.



However, there was another point about which we were both in complete agreement—*that we both wanted to respect the patient's wishes for care*. This is a critical insight. The decision how to proceed is not about what the patient's daughter wants; it's about what the patient would have wanted in this situation—although our only access to that information is through the patient's daughter.

How to proceed? Well, the fourth principle is, *so far as possible, to tie your opinions to objective criteria*. Although prediction is imperfect, there is often a lot that can be said about the medical facts. In this case, we re-consulted nephrology who confirmed that renal failure was permanent. We repeated the patient's MRI and asked neurology to revisit the consult, pushing them to commit to a likelihood of recovery. They were unable to say exactly what the final outcome would be, but were able to narrow the range of possibilities: the best case outcome would be limited ability to recognize her family, perhaps to enjoy visiting with them, but that higher function including communication was extremely unlikely and self-care was out of the question. With that information, we were able to shift the frame of the discussion from withdrawal of life support to what the patient would have wanted in the event of this sort of calamity.

Dr. P came on service on a Monday. The patient's daughter lived about an hour away and was still working full time, so she visited every other day. He met with the daughter and her husband several times, with the discussions being informed by curiosity and a desire to understand the daughter's perspective. Dr. P initially told the daughter that he needed time to make sense of a long and complex hospital course and that he wanted more information about her prospects for recovery. Once he felt comfortable with the patient's course and had gotten the best information he could, then they would meet formally to talk about long-term goals. Dr. P was doing the groundwork of breaking bad news: finding out what the person knows, sharing information (aligning and educating), responding to the person's feelings, establishing follow-up.

Dr. P, the surgeon, the daughter, and her husband met together in the ICU conference room. Dr. P had requested that the vascular surgeon who had performed the AAA repair attend because the daughter needed to hear directly from her that the surgery was the right decision, regardless of the post-operative complications. He was making sure he attended to her emotional fears and concerns. Dr. P explained the neurologist's findings and asked the daughter if she thought their

prognosis was surprising. The daughter stated that she knew that her mother would never be the person she once was. Having established that outcome in a non-threatening way, Dr. P then asked the daughter, in light of her current condition, what her mother would have wanted. The daughter immediately blurted out, “Oh, she’d never have wanted any of this!!” What do you think we should do now? “We should stop!” And the patient’s daughter started to cry. The attending then reassured the daughter she had done the best she could. What they should do now was make sure they followed the patient’s wishes. The team withdrew support the following day.

What caused this woman to be treated for two months in an ICU with no realistic hope of recovery and—apparently—against her wishes? Were her physicians “unable to face death”? No, her physicians were trying to do the best they could and believed they were being stymied. Was her daughter completely unrealistic, or difficult? No, her daughter was trying to be the best daughter she could be. The best way to explain what happened is that each side had forgotten how to talk to one another.

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## **A Guide for Conducting an ICU Family Meeting When the Patient Is Unable to Participate**

Robert Arnold MD,<sup>1</sup> Judith Nelson, MD, JD<sup>2</sup>

<sup>1</sup>Institute to Enhance Palliative Care, Section of Palliative Care and Medical Ethics,  
University of Pittsburgh School of Medicine, Pittsburgh, PA, and

<sup>2</sup>Department of Medicine, Division of Pulmonary, Critical Care and Sleep Medicine and Hertzberg  
Palliative Care Institute, Mount Sinai School of Medicine, New York, NY

### **Prepare for the Meeting**

- Review the history and medical issues.
- Coordinate health care team - attending MD(s), bedside RN, SW, palliative care clinician(s).
- Discuss goals of meeting with team.
- Identify one clinician as meeting leader.
- Discuss which family members will be present.
- Arrange a private, quiet location with seating for all.

### **Open the Meeting**

- Introduce all in attendance.
- Establish the overall goal of the meeting: e.g.,  
*Today I'd like to make sure everyone understands how [PATIENT] is doing and answer your questions.*
- Acknowledge that this is a difficult time/situation.
- Set "rules" for discussion: e.g.,  
*We have a half hour for discussion today.*

### **Elicit Family Understanding**

- Ask questions of family members:  
*Let's start by making sure we are all on the same page. How are you seeing the medical situation at this point? What have you been told? What is your understanding of the likelihood that [PATIENT] will get well enough to return home?*
- As they respond, think about:
  - What do they understand?
  - What do they believe will happen (vs. what they were told)?
  - What are their emotions?

### **Give Information**

- Think of the two points you want them to understand:
  - 1) Patient's illness and treatments
  - 2) Prognosis – what you expect re survival, recovery; what will signal improvement or deterioration
- Hints for how to give the information:
  - 1) Ask for permission:  
*Would you like me to talk about what we think is going to happen?*
  - 2) Avoid medical jargon.
  - 3) Beware of physicians' tendency to talk too much and focus on technical matters.
  - 4) Check frequently on what the family has heard:  
*What questions do you have about what I just said?*
  - 5) Be transparent about uncertainty:  
*"I wish I could be clearer about what will happen"*  
Try to identify what may bring more clarity and when you might expect this.

## **Respond with Explicit Empathy to the Family's Emotions (rather than trying to "solve" them):**

"NURSE" mnemonic:

**N**-ame *"You seem distressed [or angry or worried, etc.]"*

**U**-nderstand *"This must be very difficult for you."*

**R**-espect *"I can see how much you are trying to honor your Dad's wishes."  
"You are asking a lot of really good questions."*

**S**-upport *"We will be there to help advise you. We can talk again tomorrow."*

**E**-xplore *"Tell me more about what you are thinking/feeling."*

Don't fight, but rather, join family statements of hopefulness, using "wish statements":

*I hear how much you want him to get better.*

*I wish I could promise things would get better. I hope he gets better too.*

See if the family can hope for the best, prepare for the worst:

*We are doing everything we can in hopes your loved one will get better. I wonder, though, if you have been able to think about what if things do not go well?*

## **After Giving Information, Ask What Concerns/Questions Family Has**

*"You just got a lot of information. What questions do you have?"*

*What concerns do you have? What is unclear?"*

## **Elicit Patient (and Family) Values and Goals**

Elicit goals of all those present, especially if multiple perspectives are held.

But maintain focus on the patient's perspective:

*Given what's gone on, what would [PATIENT] say if he could see all this and speak to us himself?*

Explore what the patient valued, his attitudes on critical illness, and what would be in his best interest:

*What kinds of things were important and enjoyable for him?*

*Did this sort of discussion or situation ever come up in your family? Did you talk about similar stories in the newspaper or on TV?"*

Understand ethnic and cultural influences on communication, decision-making, family relationships, concepts of illness and death.

*"Can you help me understand what I need to know about [PATIENT]'s beliefs and practices so I can take the best care of [PATIENT]?"*

## **Deal With Decisions That Need to Be Made**

Begin with the patient's values and then turn to specific interventions if necessary. Defer discussion of specific therapies (e.g., mechanical ventilation) until the general goals are clarified:

*It sounds like [PATIENT]'s primary goal was to be able to independent. And if that could not happen, he wanted to avoid being stuck on a breathing machine?*

Offer clear recommendations based on patient and family goals:

*Given our understanding of the medical situation and what you've told us about [PATIENT]'s goals, I do not recommend dialysis."*

*Given what we know and have heard, Dr. D could you make a recommendation about what treatments would help?*

Do not offer treatments that are inappropriate (i.e., you believe burden outweighs benefit).

Do not speak of withdrawing "care" or "treatment."

If appropriate, frame the decision as a “therapeutic trial” or as a health care team recommendation that requires only family assent.

*It sounds like we should try the treatment for about a week and see if he is better.*

*Dr. D, can you explain what you think would be best to try and how we will know if this plan is working?*

### **Close the Meeting**

Offer a brief summary of what was discussed.

Review what is going to be done to try to achieve the patient’s goals and what will indicate whether the patient is better or worse.

Offer to answer questions, then or later

*As you think about what we have talked about, I expect you will have questions. Feel free to ask me, now or later.*

Check in to make sure they heard what you wanted them to hear

*I want to make sure we are on the same page. If you were going to tell someone about this meeting, what would you say we talked about?*

Express appreciation and respect for the family:

*I want to thank everyone for being here and for helping to make these difficult decisions.*

Check in with the family about their needs, offer to help them.

Repeat caution about unpredictability of critical illness and treatment response, but reassure about continuing communication and patient care.

*Sometimes unexpected things happen. We will contact you as soon as possible.*

Make a clear follow-up plan, including for next family meeting.

**Document the meeting in the chart so that the entire healthcare team is aware of what was discussed.**

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**SEE NEXT PAGE** for a selection of mnemonics.

## SELECTED MNEMONICS FOR FAMILY MEETINGS

- ▶ The “**NURSE**” mnemonic (Tulsky et al.) for explicit expression of empathy:
  - N**-ame “*You seem distressed [or angry or worried, etc.]*”
  - U**-nderstand “*This must be very difficult for you.*”
  - R**-espect “*I can see how much you are trying to honor your Dad’s wishes.*”  
“*You are asking a lot of really good questions.*”
  - S**-upport “*We will be there to help advise you. We can talk again tomorrow.*”
  - E**-xplore “*Tell me more about what you are thinking/feeling.*”
  
- ▶ Some clinicians like to use the “**SPIKES**” (Baile & Buckman) mnemonic for family meetings:
  - S**= Set up situation
    - Privacy
    - Kleenex
    - All appropriate participants
  - P**= Find out patient or family **P**erception of the medical situation
  - I**= Invitation - How much information is wanted?
  - K**= **K**nowledge
    - Foreshadow
    - Speak in simple and straightforward terms
    - Stop and check for understanding
  - E**= Use **E**mpathic statements when responding to emotions
  - S**= Strategy – what is going to be done next
  
- ▶ The University of Washington End-of-Life Care Research Group proposed the “**VALUE**” mnemonic for ICU family meetings:
  - V**-alue and appreciate what the family has said
  - A**-cknowledge the family’s emotions
  - L**-isten and
  - U**-nderstand the patient as a person by asking questions
  - E**-licit the family’s concerns and questions
  
- ▶ The “**ASCEND**” mnemonic was developed by Dr. Karen Knops:
  - A**-Anticipate (pre-meeting planning)
  - S**-Summarize (patient/family summarize their understanding first)
  - C**-Acknowledge concerns of patient/family
  - E**-Explore/Explain (goals, medical information, appropriate trial of treatment)
  - N**-Next steps
  - D**-Document

## CRITICAL CARE COMMUNICATION (C3)

### READING AND RESOURCE LIST

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