



National Hospice and Palliative Care Organization  
**Palliative Care Resource Series**

**FINDING CALM IN THE STORM:  
A PALLIATIVE CARE APPROACH TO  
NAVIGATING THE FAMILY MEETING**

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## INTRODUCTION

Family meetings during medical crises, especially when end-of-life care issues will be discussed, can prompt anxiety and fear among providers and families. This paper will describe an approach towards effective family meetings by reviewing:

- pre-conceptions and personal history providers might take into the meeting,
- some of the research behind family meetings,
- a general outline for family meetings, and
- pitfalls and challenges that might occur.

## PRECONCEPTIONS AND PERSONAL HISTORIES

Healthcare providers may bring into family meetings certain pre-conceptions resulting from their own histories as family members and their prior experiences as providers.

**A care provider's personal definition of family may create a bias as to who should be present during a family meeting and how those family members should behave.** Patients may define the word "family" in many different ways. There are families of origin and families of choice. There are biological families, blended families, and adoptive families, gay, lesbian and straight families. Very few families fit the idealized and perhaps stereotypical family of advertising and television where there is no substance abuse or yelling, and everyone gets along.

For the purposes of a family meeting, family must be defined by the patient. Family can include friends, aunts, uncles, cousins, co-workers, teammates, or platoon members. If the patient is unable to define family and there is no documentation available, providers will need to interview any available family or friends and/or use their best judgment. The intent is to be sure that the people in the room are the people the patient would want to have in the room.

**Pre-conceptions of the patient's and family's suffering may differ from the reality of their experience.** We cannot presume to understand someone else's experience unless we really listen to their story with an open mind and an open heart. If we cannot be genuinely open, most families will quickly perceive this and shut down communication.

As providers we often have a need to rationalize and organize a patient and family's physical and emotional distress into models that make sense to us. The family may need to simplify and make sense of the chaos imposed by our system of fragmented healthcare. Serious illness, prolonged hospitalization, or an ICU stay can leave family members experiencing post-traumatic stress disorder months or even years after a loved one has died.

**Recognize the mutual experiences of fatigue and exhaustion brought into the family meeting room.** Providers experience long stressful days as well as nights on call. Families coping with a loved one's serious and critical illness find themselves immersed in a foreign and stressful environment where a strange language is spoken and cultural norms are alien.

**Often providers and families have “circled the wagons” and assumed a defensive posture before the meeting even begins.** Providers create their own legends and stories about families, passed in whispers, winks, and nods. “Well they’re just keeping him/her alive for the money;” or “They’ve already threatened to sue!”

## WHAT DO WE KNOW?

- Families and caregivers rate end-of-life care in hospices as excellent, but the majority perceive that there is inadequate communication and contact with physicians in the hospital and inadequate help with emotions in that setting as well. Overall, 38% of the families of patients cared for at the end-of-life in hospital receive poor family support by their own estimate (Teno J, et al. *JAMA* 2013; 309: 470-477. Teno J, et al. *JAMA*. 2004; 291: 88-93).
- When families are better prepared through advance care planning, they have less stress, anxiety and depression; they are less likely to report communication problems; and they ultimately feel better prepared for a loved one’s death while reporting an overall higher satisfaction with care.
- Most families are poorly prepared for facing end-of-life decisions. When end-of-life decisions have to be made by family members, half or more of them are not aware of the patient’s preferences. Families who felt unprepared suffer a greater burden of grief and its potential complications (Lautrette A, et al. *Crit Care Med*; 2006; 34:S364-S372. Schaefer KG, Block SD. *Curr Opin Crit Care*. 2009; 15:569-77. Billings JA. *J Palliat Med*. 2011; 14:1042-1050).
- Life sustaining care is almost always the default and many institutions have no integrated systematic approach to end-of-life care. Likewise, institutions lack a means for recording patient wishes, modifying them when necessary and retrieving them easily during crisis (Bernacki RE and Block SD. *JAMA Intern Med*. 2014).
- Most providers are uncomfortable communicating prognosis to patients and families because of uncertainty and a fear that they will be held to a specific prediction. They want to be optimistic and do not want to be perceived as taking away hope. A recent study suggested that families wish to hold on to optimistic predictions and that their approval of providers is highest for those who offer such predictions (Chiarchiaro J, et al. *Crit Care Med*. 2015; 43:542-548).
- When caregivers are burdened with decisions, they may default to treatment so as to avoid the guilt implicit in a conservative approach, especially when such an approach is presented as “doing nothing”.
- The burdens of end-of-life decisions for families are many (Radwany S, et al. *Am J Hospice and Palliative Med*. 2009; 26: 376-83.) including: lingering questions about decisions or recommendations from healthcare providers; persistent resentments regarding those decisions; and guilt over having acceded to physician recommendations.
- Many families perceive that providers in different areas and specialties reside in silos of care, none of which communicate or coordinate with one another for the betterment of the patient (Stacey C; Pai M, Radwany S. *American Academy of Hospice and Palliative Medicine Annual Meeting* 2015).
- “Moral distress” has entered the lexicon in the realm of nursing when the ethically appropriate action is known to nurses but they are unable to act upon it. Likewise, physicians are not immune from such stresses, especially when they feel forced into treatments and actions which are not in the best interest of the patient. ([www.aacn.org/WD/Practice/Docs/Moral\\_Distress.pdf](http://www.aacn.org/WD/Practice/Docs/Moral_Distress.pdf) 8/2008).

Given what we understand, it is encouraging to know that effective family meetings can help. Proactive and structured family meetings have improved a broad range of outcomes in over a dozen trials, most of them focused on family meetings in the ICU. Family meetings can result in better family understanding and acceptance of the clinical situation, and decreased post-traumatic stress disorder and complicated grief in survivors.

When meetings, planning, and decisions are perceived as effective and appropriate, there is better nurse assessed quality in death, as well as shortened length of stay and lowered costs (Lautrette A, et al. Crit Care Med; 2006;34:S364-S372. Schaefer KG, Block SD. Curr Opin Crit Care. 2009; 15:569-77. Billings JA. J Palliat Med. 2011; 14:1042-1050).

## THE FAMILY MEETING: A LEARNED AND REPRODUCIBLE SKILL

Over the past two decades, an extensive body of literature has been written concerning the family meeting. Lists and mnemonics have been developed including SPIKES, ABCDE, etc. The components presented here come without a mnemonic.

**1. Preparation can mean everything.** The first question is: “Who should be there?” As discussed earlier, if at all possible the patient should provide permission as to who can attend and participate in the decision making. The spouse or guardian, the durable power of attorney for healthcare, immediate and extended family members, friends and other loved ones should be included. It is always helpful to include the bedside nurse in the hospital setting or the home nurse or hospice nurse in other settings; social workers and chaplains or other healthcare providers may also be appropriate. In order to accommodate out of town family members, a speaker phone or simply a mobile phone with a speaker works well and alleviates the stress felt by those at a distance.

Make sure there is ample room for all to sit comfortably and for discussion to proceed without interruption. It is always helpful for providers to sit close to the door or egress, not only to escape a potentially violent situation, but also to exit easily giving the family time to discuss and process what they’ve been told. Accommodate elderly or frail individuals as they may be the most important participants. Encourage everyone to turn off their cell phones, and their pagers, or to leave them with someone else.

**2. Every family meeting requires a pre-meeting or huddle in advance, as well as a debriefing with important providers to assure a common understanding of goals.** Make sure that a proper location and time for the meeting has been decided upon and communicated. Potential goals of the meeting are: (Billings JA. J Palliat Med.2011; 14:1042-1050):

- to assess understanding, concerns and coping
- to share information and provide education
- to provide emotional support for the family
- to build trust
- to elicit patient goals and values and use these to establish goals of care
- and finally to support and educate healthcare team members as well

**3. Start the meeting with clear introductions of the names and roles of the healthcare providers in the room.** Share the names and relationships of the family members. Always sit during a family meeting and avoid checking your watch, phone, or pager. Even a glance at the clock will be read by family members as impatience and the desire to be somewhere else.

**4. Use a trigger at hand to start the conversation – a ring, a watch, and a picture – anything that might be important to the patient and to the family and symbolic of their relationships or of the patient’s unique story.** Simply ask:

- “Tell me about \_\_\_\_\_.”
- “Where did he grow up?”
- “What did she do?”
- “What was important to him?”
- “What most impressed you about her?”

Questions like these can provide a greater depth of understanding of the patient and family.

**5. Establish what the patient and family know and what they have been told.** Never assume that you know what they know or understand. Consider opening the discussion by asking: “Please tell me what has happened up to now?” You might follow with, “What have the doctor’s told you about what has happened?” After they tell their story, ask, “What do you think about all of this?” An essential goal is to help the family speak more than you do. This requires patience, silence, encouragement, and appropriate open ended questions.

**6. The next step is acknowledgement.** Families need to know they are heard, understood and appreciated. Reflect back on what you have heard and clarify your understanding of their understanding of the patient’s narrative and medical reality. If they express anger and frustration, it is reasonable to assume that they have a good reason to feel that way. It is also important to guide or prevent a single outlier in the family from dominating the conversation. Try not to be defensive and avoid denying anyone’s version of what has occurred unless it is so far removed from reality that clarification is needed.

**7. Affirm the care the family has provided for their loved one (as long as you can do so honestly).** You might say:

- “You and he have been through a lot.”
- “I can’t imagine dealing with everything you and your family have faced”
- “I’m sorry about what’s happened. I’ll look into it. I know we need to do better for you and for him” (If you say you’re going to look into it, then you must look into it and get back to the family as quickly as possible – preferably within 24 hours)
- “You have been a great advocate and caregiver for \_\_\_\_\_.”

**8. Clearly and succinctly communicate the patient's prognosis to the family.** This should, of course, be preceded by an assessment of their desire and readiness to hear prognostic information. Also, assess your own readiness and concerns. How will your own comfort with the prognosis and its communication affect your communication with the family? What is your level of certainty? What is your anxiety level going into this meeting? This kind of personal self-assessment should precede the meeting and allows you to take your own temperature before entering a potentially charged situation and making it worse.

**9. When communicating the patient's prognosis be clear, concise, and empathic.** Avoid euphemisms and jargon whenever possible. Rather than saying: "The pulmonary metastases have made his survival untenable" try: "The cancer has spread to his lungs and will result in his death." Communication of absolute certainty is likely to be off-putting to families and misleading. It is more helpful to use ranges in prognosis such as: hours to days, days to weeks, weeks to months, months to years, or years. While discussing expected survival, we must also be clear about the patient's expected future functional state.

**10. When presenting the family with expected or unexpected bad news, the essential next step is to offer empathy and support.** Allow silence for the family to process the information and express their feelings. Consider counting to 20 or 30 silently to give the family the time they need. A useful mnemonic to improve communication of empathy and support to families is VALUE (Curtis JR, White JB. Chest 2008; 134:836-843):

- V** – Value comments made by the family
- A** – Acknowledge family emotions
- L** – Listen
- U** – Understand the patient as a person
- E** – Elicit family questions

Provide non-verbal support by leaning over, touching a hand, or putting your hand on someone's shoulder. Offer tissues if necessary. Ask them to help you understand what is making them upset, scared, or sad. Explore their feelings further with questions like: "Tell me more?" Express empathy. "I am sorry is always appropriate." "I wish" statements may help you express your empathy and support (Quill TE, Arnold RM, Platt F. Annals Intern Med. 2001; 135: 551-555):

- "I wish I had better news to give you."
- "I wish things had turned out differently."
- "I wish it were possible for us to fix this."
- "I wish we had an effective treatment for this."

**11. Establish goals of care.** They must always be placed in the context of the patient’s values, with the medical reality of the situation defining the potential outcomes. Goals of care do not necessarily represent an either/or decision regarding traditional versus palliative care:

- One can attempt to cure disease while relieving suffering;
- One can work to prolong life while improving or preserving the quality of life;
- One can aim to improve function while trying to keep the patient and family in control;
- One can strive to avoid a premature death while still reassuring a good death;
- One can hope to restore the patient’s professional and family roles, while supporting the family emotionally as well

**12. Assess what the family has heard from you and what their understanding is.** Do this delicately so the family doesn’t feel like you’re testing them. A helpful question is, “Are there others you’ll be speaking with about this? What will you tell them?” Another option could be: “We’ve covered a lot of ground today and I need to be sure I am speaking clearly. What are the most important things you’ve heard today?” The answers to these questions may cause you to double back and double down on your prior communication.

**13. Review the plan of care and plan to follow-up after this family meeting.** Summarize the most important information and then review the overall plan – the big picture. Agree upon a follow up meeting or touch base, especially if a therapeutic trial is being undertaken. This is a good time to introduce other sources of support such as pastoral care, social work, counseling, psychology, etc.

**14. Finally, put something in writing for the patient and family, as well as for physician colleagues.** A written document will assure better understanding and continuity of care. Promises regarding follow up and touching base must be kept.

## PITFALLS AND CHALLENGES

**1. Too much information.** Upon analysis of videotaped family meetings in Intensive Care Units, several errors by healthcare providers have been consistently identified (Curtis JR, et al. Am J Respir Crit Care Med 2005; 171: 848.4-9):

*Providers:* spend more time talking than the patient and family; do not tolerate silence; pass over emotions; miss teaching opportunities. As a result, families may feel that they have not been heard and that their suffering and the patient’s suffering has not been acknowledged.

**2. Binary framing.** This results when a provider sees only two possible outcomes from a difficult conversation and where alternative explanations or information is not explored. Stress and lack of time may force us to oversimplify a situation and not see the gray areas involved (Manzoni JF. Harvard Bus Rev. Sept 2002: 114-119).

**3. Communication styles.** Families may not hear what we think they hear or visualize what we think they visualize. This has been well-illustrated in a series of important studies by Volandes on comparing verbally presented hypothetical end-of-life decisions with a 2 minute video visually demonstrating potential patient outcomes. Decisions change dramatically when a video is reviewed as compared to a verbal description alone. Differences in decision making purportedly related to race and health literacy disappeared after watching the video (Volandes AE, et al. *J Palliat Med.* 2008; 11: 700-706).

**4. Loaded vocabulary.** Some families put us on the defensive by using loaded vocabulary. It is essential to address their questions directly and honestly. They ask if we might be starving a patient by not providing artificial nutrition or if we're killing a patient with strong pain relievers. You might respond by explaining:

- "Part of dying naturally is that people stop eating and drinking. This protects them from excessive secretions, swelling, and to some extent leakage of urine and stool."
- "At this point in her illness, she is no longer able to process nutrition and even fluids."
- "Good mouth care prevents the sensation of thirst or hunger in people who are dying."

Regarding whether the pain medicine is resulting in the patient's death you might reply: "Using the right amount of pain medicine might actually help her live longer as well as better, although she may sleep just a bit more. It is very helpful to anticipate and elicit these concerns preemptively as the questions from the family will linger long after the patient is gone.

**5. Escalating emotions.** It would be most effective if we could titrate our emotional state in the opposite direction of the family's emotional state as meeting tensions escalate. When families become angrier and their voices get louder, it is time for us to become calmer, and to lower our voices slightly.

Becoming a 'participant – observer' standing aside from the argument can be helpful. If an apology is necessary, present it clearly and honestly, but set boundaries and be sure to maintain your own safety. Seek support after the meeting so that you can decompress. Always look for options that meet the needs of all the parties involved if at all possible. (Back AL, Arnold RM. *JAMA.* 2005; 293: 1374-1381. Weeks H. *Harvard Bus Rev.* July-Aug 2001: 112-119. Lown BA. *South Med J.* 2007; 100:34-39).

**6. Unrealistic expectations.** Expecting to get too much done in an especially loaded and tense situation may be unrealistic. A first meeting may be needed just to establish trust and trade information. Families will need time and guidance to accept the tragic and rapidly changing circumstances which have been thrust upon them.



**7. Boundaries of language and culture.** When using an interpreter, it is essential to use a trained professional for medically related issues. It is essential to brief any interpreter in advance about the nature of the discussion. Prepare the family for the meeting, assuring confidentiality and explaining the role of the interpreter. Always speak directly to the patient and family and not simply at the interpreter. Use simple and short sentences wherever possible. Don't forget that empathic statements are still necessary. Debrief the interpreter to see if there were important verbal and non-verbal messages you missed. Check to see if the interpreter needs help in processing and decompressing from the meeting (Schenker Y, et al. J Palliat Med. 2012; 15:494-498).

Regarding cultural issues, it is best to query with an open and respectful curiosity. The most common cultural differences lie in:

- patient autonomy
- the disclosure of diagnosis and prognosis
- respect for authority
- filial piety
- spirituality and trust
- the locus of control and family role in decisions.

Work directly with the patient in order to gain his/her permission to inform others and to assess the patient's desired level of involvement. Assessing how decisions are made and the sources of spiritual support for the patient and family will prove enlightening and helpful in developing the plan of care. (Sharma RK and Dy SM. Am J Hospice and Palliativ Med. 2011; 28:437-444).

## SUMMARY

Following are some essential components of the effective family meeting:

- Have a plan and confirm it with the team; determine, with the patient, if possible, who should be present, where the meeting should take place and when it will take place;
- Start with introductions and ground rules;
- Assess what the family knows and what they want to know;
- Speak less than the family does and be willing to tolerate silence;
- Provide information and prognosis clearly and concisely – avoid the use of jargon;
- Acknowledge emotions;
- Assess understanding;
- Don't force decisions prematurely;
- Support and ease guilt wherever possible
- Summarize and provide follow up.

As we come to understand the background and depth within a family and the nature of their relationships, it is hard to walk away from a family meeting without having been changed and enlightened. While it is normal to have some anxiety at the start, family meetings can leave providers with a sense of accomplishment and well positioned to facilitate good decisions for both the patient and family.