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Communicating with Patients and Families About Difficult End of Life Decisions: A Guide for Medical Providers

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**COMMUNICATING WITH PATIENTS AND FAMILIES
ABOUT DIFFICULT END OF LIFE DECISIONS:
A GUIDE FOR MEDICAL PROVIDERS**

Jim deMaine, M.D. & Joi Murotani Dennett, MSW, LSWAIC ***

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I. INTRODUCTION

Advance directives, which commonly include living wills and durable power of attorney for health care, are promoted as useful documents for decision making at end of life (EOL) and have a statutory basis in all fifty states.¹ However, these documents are often not completed or, if completed,

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are not adequate to address specific issues. Critiques of advance directives question their utility in allowing a patient to have their wishes accurately understood and complied with when they may become incompetent in the future.²

In order to deal with difficult decisions and to clarify the patient's values and wishes about medical treatment, family-centered shared decision making between patient (or surrogate) and their respective physician is a widely recommended approach.³ Despite this recommendation, there is evidence that clinicians may fail to carry out adequate communication when dealing with EOL discussions with patients and families.⁴

In conferring with multiple families over many years, we⁵ have developed a method for case conferences which promotes shared decision

¹ Charles P. Sabitino, *Death in the Legislature: Inventing Legal Tools for Autonomy*, 19 N.Y.U. REV. L. & SOC. CHANGE 309, 315–16 (1992) (describing the statutory basis for advance directives in the states).

² See generally Kristi L. Kirschner, *When Written Advance Directives are Not Enough*, 21 CLINICS GERIATRIC MED. 193, 193–209 (2005) (criticizing advance directives); Thaddeus Mason Pope, *The Maladaptation of Miranda to Advance Directives: A Critique of the Implementation of the Patient Self-Determination Act*, 9 HEALTH MATRIX 139, 156–80 (1999) (suggesting that advance directives are not based on a real understanding of patients); Mark R. Tonelli, *Pulling the Plug on Living Wills: A Critical Analysis of Advance Directives*, 110 CHEST 816, 816–22 (1996) (analyzing the utility of advance directives).

³ See, e.g., J. Randall Curtis & Mark R. Tonelli, *Shared Decision-Making in the ICU: Value, Challenges, and Limitations*, 183 AM. J. RESPIRATORY & CRITICAL CARE MED. 840, 840–41 (2011) (exploring the pros and cons of shared decision making); J. Randall Curtis et al., *Studying Communication About End-of-Life Care During the ICU Family Conference: Development of a Framework*, 17 J. CRITICAL CARE 147, 147–48 (2002) (stating the importance of successful communication during ICU family conferences); Michael W. Rabow et al., *Supporting Family Caregivers at the End of Life: "They Don't Know What They Don't Know,"* 291 JAMA 483, 488–89 (2004) (explaining the role of the physician during end of life discussions); Robert D. Truog et al., *Recommendations for End-of-Life Care in the Intensive Care Unit: The Ethics Committee of the Society of Critical Care Medicine*, 29 CRITICAL CARE MED. 2332, 2333 (2001) (emphasizing the importance of open communication between the family and physician); James A. Tulsky, *Beyond Advance Directives: Importance of Communication Skills at the End of Life*, 294 JAMA 359, 359–65 (2005) (stressing that advance care planning should emphasize patient and family emotions and focuses more on goals for care); Douglas B. White & J. Randall Curtis, *Establishing an Evidence Base for Physician-Family Communication and Shared Decision Making in the Intensive Care Unit*, 34 CRITICAL CARE MED. 2500, 2500–01 (2006) (stating the importance of shared decision making in the ICU); Douglas B. White et al., *Toward Shared Decision Making at the End of Life in Intensive Care Units: Opportunities for Improvement*, 167 ARCH. INTERNAL MED. 461, 461–67 (2007) (concluding that shared decision making about end-of-life treatment choices is often incomplete).

⁴ White et al., *supra* note 3, at 461–65 (concluding that shared decision making about end-of-life treatment choices is often incomplete); see generally Curtis & Tonelli, *supra* note 3, at 840–41 (stating that physicians may not communicate effectively using the shared decision making model).

⁵ The authors worked together in the ICU for at least two decades and developed this method for case conferences, with input from other medical providers, patients, families, and the ethics committee.

making.⁶ We have found that, in the emotionally charged atmosphere of EOL discussions, a structured path of deliberation with families allows for the participants to communicate more effectively with each other and the medical providers.⁷

II. COMMUNICATION ISSUES AFFECTING END OF LIFE DECISIONS

Approximately one half of patients dying in the hospital are cared for in the Intensive Care Unit (ICU) and the majority of deaths in the ICU involve withholding or withdrawing life-sustaining treatments.⁸ Unfortunately, EOL issues are frequently not discussed or clarified until a crisis occurs.⁹ The discussions are time consuming and the physician may be inexperienced or untrained as an effective facilitator in this discussion.

The importance of teaching physicians to use effective communication skills during EOL discussions is being recognized as a key factor in truly meeting patient values and wishes.¹⁰ A strategy including giving the parties a brochure and increasing time for discussion was found to decrease post-traumatic stress and depression in family members,- thus lessening the burden of bereavement.¹¹

Active listening¹² and increased time for family speech¹³ also help to improve family satisfaction. Saying, “I am sorry that ...” can be problematic in that it may sound like gratuitous sympathy or even imply a mistake in treatment.¹⁴ Clinicians empathetically saying “I wish things were different” can be more helpful when responding to loss or unrealistic hopes.¹⁵

⁶ See *infra* Part III (discussing the appropriate methodology for patient care conferences regarding seriously ill patients).

⁷ See *infra* Part III (laying out the various steps in properly conducting a patient care conference for seriously ill patients).

⁸ Curtis et al., *supra* note 3, at 147.

⁹ See *id.*

¹⁰ See Daniela Lamas & Lisa Rosenbaum, *Freedom from the Tyranny of Choice — Teaching the End-of-Life Conversation*, 366 NEW ENG. J. MED. 1655, 1655–57 (2012) (emphasizing the importance of using effective communication skills during end of life discussions).

¹¹ Alexandre Lautrette et al., *A Communication Strategy and Brochure for Relatives of Patients Dying in the ICU*, 356 NEW ENG. J. MED. 469, 477 (2007) (revealing techniques for reducing post traumatic stress in family members).

¹² Craig M. Lilly & Barbara J. Daly, *The Healing Power of Listening in the ICU*, 356 NEW ENG. J. MED. 513, 513–14 (2007) (stating the importance of listening during end of life discussions).

¹³ J.R. McDonagh et al., *Family Satisfaction with Family Conferences About End-of-Life Care in the Intensive Care Unit: Increased Proportion of Family Speech is Associated with Increased Satisfaction*, 32 CRITICAL CARE MED. 1484, 1487 (2004) (allowing increased family member discussion improves family discussion).

¹⁴ Timothy E. Quill et al., *“I Wish Things Were Different”: Expressing Wishes in Response to Loss, Futility, and Unrealistic Hopes*, 135 ANNALS INTERNAL MED. 551, 551–52

In a large study, “only 47% of physicians knew when their patients preferred to avoid CPR [cardiopulmonary resuscitation].”¹⁶ Shockingly, 46% of do-not-resuscitate (DNR) orders were written within two days of death.¹⁷ To address this shortcoming, the EOL discussion should initially focus primarily on CPR or ventilators. However, excessively concentrating on the issue of CPR may divert the important discussion of a patient’s goals and values leading to a broader discussion of the options for patient care.¹⁸

For effective communication, there needs to be coordinated and appropriate roles for all the stakeholders involved in the care of the patient. This includes palliative care,¹⁹ nursing, social service,²⁰ and spiritual care.²¹ Moral distress in the caregivers, often surfacing when conflict arises, should be recognized and addressed.²²

Physicians need to be aware of state law, specialty guidelines,²³ and hospital policy when participating in EOL discussions. Physicians must understand legal primers,²⁴ legal myths,²⁵ and the problems with invoking

(2001) (discussing the importance of showing sympathy without inferring a mistake in treatment).

¹⁵ *Id.* at 551, 552–55.

¹⁶ SUPPORT Principal Investigators, *A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments*, 274 JAMA 1591, 1591 (1995).

¹⁷ *Id.*

¹⁸ See John M. Luce & Douglas B. White, *The Pressure to Withhold or Withdraw Life-Sustaining Therapy from Critically Ill Patients in the United States*, 175 AM. J. RESPIRATORY & CRITICAL CARE MED. 1104, 1106 (2007).

¹⁹ See Joseph Sacco et al., *The Effects of the Palliative Medicine Consultation on the DNR Status of African Americans in a Safety-Net Hospital*, AM. J. HOSPICE & PALLIATIVE CARE, 5 (2012), available at <http://ajh.sagepub.com/content/early/2012/06/13/1049909112450941.long>.

²⁰ Susannah L. Rose & Wayne Shelton, *The Role of Social Work in the ICU: Reducing Family Distress and Facilitating End-of-Life Decision-Making*, 2 J. SOC. WORK END LIFE & PALLIATIVE CARE 3, 3–23 (2006) (discussing the importance of social workers in the ICU).

²¹ See Richard J. Wall et al., *Spiritual Care of Families in the Intensive Care Unit*, 35 CRITICAL CARE MED. 1084, 1089 (2007) (concluding that family satisfaction is increased by involvement of a spiritual advisor) (discussing the role of spiritual care in the ICU).

²² Ellen H. Elpern et al., *Moral Distress of Staff Nurses in a Medical Intensive Care Unit*, 14 AM. J. CRITICAL CARE 523, 530 (2005) (calling for intervention in moral distress of critical care nurses).

²³ See Truog et al., *supra* note 3, at 2338–45 (recommending comparison of the indicated treatments with the possibility of cure).

²⁴ See generally W. Eugene Basanta, *Advance Directives and Life-Sustaining Treatment: A Legal Primer*, 16 HEMATOLOGY/ONCOLOGY CLINICS N. AM. 1381, 1381–96 (2002).

²⁵ See generally Alan Meisel et al., *Seven Legal Barriers to End-of-Life Care: Myths, Realities, and Grains of Truth*, 284 JAMA 2495, 2495–501 (2000) (identifying critical legal myths and recommending strategies to improve care).

futility²⁶ in order to guide discussions appropriately and to understand when to request legal advice or, in a rare case, court action.²⁷ Risk management education for physicians can help alleviate a lack of knowledge in these areas. When needed, physicians can obtain additional support from their respective institution's legal department.

The physician must also have an understanding of the ethical issues involved in EOL care and the role of an Ethics Committee (EC) in their institution. Indeed, there are some similarities between a patient care conference and an EC consultation.²⁸ Ideally, the institution's EC will have staff education as one of its important roles.

We recommend the use of a structured and clear format in discussing EOL care for seriously ill patients. Learning this methodology requires experiential practice with careful overview and feedback by trained clinicians. Some might argue that the EOL conference takes too much time, however our experience is that shortcuts to decisions may generate distrust and delays that actually require more critical time to try to remedy a communication breakdown.

Communication breakdowns are likely to occur in a number of situations, including, but not limited to: when a stakeholder feels left out or ignored in the decision-making process; when physicians appear rushed or arrogant and try to push the decisions without allowing for processing time ; when there is a perception of lack of transparency; when specialists give conflicting opinions; when the family feels the patient's wishes are being ignored; and when the family is dysfunctional particularly when drug use or alcoholism is involved.

²⁶ See generally SUSAN B. RUBIN, WHEN DOCTORS SAY NO: THE BATTLEGROUND OF MEDICAL FUTILITY (David H. Smith & Robert M. Veatch eds., 1998); Thaddeus M. Pope, *Legal Briefing: Futile or Non-Beneficial Treatment*, 22 J. CLINICAL ETHICS 277, 277–96 (2011); Douglas B. White & Thaddeus M. Pope, *The Courts, Futility, and the Ends of Medicine*, 307 JAMA 151, 151–52 (2012) (stating the justification for a court limited role in futility cases); Eva C. Winkler et al., *Evaluating a Patient's Request for Life-ProLonging Treatment: An Ethical Framework*, 38 J. MED. ETHICS 647, 647–51 (2012) (arguing that neither the concept of futility nor that of patient autonomy alone is apt for resolving situations in which physicians are confronted with patients' requests for active treatment).

²⁷ White & Pope, *supra* note 26, at 151–52.

²⁸ See Cynthia M.A. Geppert & Wayne N. Shelton, *A Comparison of General Medical and Clinical Ethics Consultations: What Can We Learn from Each Other?*, 87 MAYO CLINIC PROC. 381, 387 (2012) (comparing patient care conferences with an ethics committee consultation); Winkler et al., *supra* note 26, at 647–51 (establishing a framework for the physician or ethics consults to discuss patient's treatment decision).

III. METHODOLOGY FOR A PATIENT CARE CONFERENCE IN SERIOUSLY ILL PATIENTS

A. Step One: Beginnings

1. Case Selection

In addition to the attending physician, a number of people can help initiate a conference. Nurses and social workers often identify issues needing resolution through their frequent interactions with patients and their respective families.²⁹ Furthermore, there are several situations where conferences have proved particularly useful: (1) withholding or withdrawing a treatment, particularly where there is a struggle or disagreement with how to proceed; (2) intensity of future treatments such as a feeding tube or dialysis; and (3) CPR status.³⁰ The patient's goals, hopes, and fears often need discussion and clarification.³¹ Communication, cultural, and language issues can best be addressed by convening everyone involved and having the appropriate resources such as a translator available.³²

2. Conference Attendees and Location

It is best to arrange a meeting with all the stakeholders available. These may include the patient, family, physicians, nurses, other providers (such as respiratory therapists), social worker, and pastor. For relatives who cannot be present, it is helpful to have a conference phone available. If a stakeholder is excluded, they may feel alienated and become obstructive to decision-making. Social workers can actively participate in the discussion and help to keep it focused. Meeting in a quiet, private, comfortable area with cell phones off helps improve communication. An experienced attending physician, nurse, or social worker should be chairperson and lead the group through the case conference method. Successful leadership requires mentoring and experience and critical EOL decisions should not be left to a junior or inexperienced person.³³ Attending physicians should also reach a consensus about the medical prognosis before the meeting begins.

²⁹ Curtis et al., *supra* note 3, at 158 (stating that successful communication during ICU family conferences will help to identify issues needing resolution).

³⁰ See Timothy E. Quill et al., *Discussing Treatment Preferences with Patients who want "Everything,"* 151 ANNALS INTERNAL MED. 345, 346–47 (2009) (discussing under what situations conferences are useful).

³¹ See *id.* at 347–48.

³² White et al., *supra* note 3, at 461–62 (explaining the importance of involving everyone during discussions).

³³ White, *supra* note 3, at 2500-01 (stressing the importance of an experienced leader during the case conference).

B. Step Two: A moral community

First, it is important to explain the outline for the discussion process. Everyone present should introduce themselves and explain their role in the care of the patient.³⁴ Decide prior to the meeting who is to keep notes and how – whether by hand or through some other means.³⁵ The chair will then outline the use and importance of a structured format for the discussion and introduces the concept of a moral community.

Next, an opening statement should be given, setting the tone with values and objectives for the meeting. If the patient is absent, recognize that fact and point all discussion toward the patient, expressing a desire to come to an agreement on what he or she would want, while also sharing the difficulties of knowing what the patient’s wishes are.. State that good will is assumed, that all input is welcome and all perspectives are valued. Medical providers must communicate warmth and caring.³⁶ Setting the tone in this way allows the group to begin forming common values and goals for the discussion. It is important that the group realizes that there are not always clear “right or wrong” answers-that is, values may conflict. Medical providers need to make clear that disagreement about values is quite permissible.

C. Step Three: Medical information

The attending physician should lead a discussion of the patient’s medical status in lay terms, presenting such information as x-rays, laboratory data, and a time line of the illness.³⁷ The time line should include previous outpatient contacts, if any, and the course of the patient’s care up to the present. This process allows families to view the patient’s medical status as a structured progression rather than a series of isolated events. Physicians frequently overestimate the amount of medical information that the family

³⁴ Curtis, *supra* note 3, at 151; see Luce & White, *supra* note 18, at 1106.

³⁵ See B. Taylor Thompson et al., *Challenges in End-of-Life Care in the ICU: Statement of the 5th International Consensus Conference in Critical Care: Brussels, Belgium, April 2003: Executive Summary*, 32 CRITICAL CARE MED. 1781, 1783 (2004) (identifying problems with end of life care in the ICU including incomplete documentation in the medical records).

³⁶ See Curtis, *supra* note 3, at 152 (stating that successful communication during ICU family conferences will help to identify issues needing resolution).

³⁷ See Thompson, *supra* note 35, at 1783 (discussing the importance of physicians fully explaining the patient’s medical condition).

understands.³⁸ Adequate time for questions and clarification of factual information improves the conference outcome.³⁹

D. Step Four: Patient preference

Medical providers need to next focus on the patient as a whole person, such as the patient's life, activities, interests, and attitudes.. A critical area of clarification for medical providers is to discern who may speak on the patient's behalf. These discussions may include the advance directive and durable power of attorney, if available. It is also helpful to talk more about the practical aspects of daily life than abstract ideas about "quality of life." Eliciting input from everyone present, and acknowledging those stakeholders who may be absent will ensure that the medical provider gathers the full range of input. Although it can be difficult, the medical provider should try to come away with a picture of what the patient really values and would wish for.⁴⁰

E. Step Five: Medical prognosis

The attending physician should give a medical prognosis and be as informative as possible, referring to tangible experiences and medical literature. Furthermore, storytelling can be an effective way of painting a picture of care, and it is often useful for physicians to discuss their personal experiences with similar patients. Discussing other cases and their outcomes helps the family recognize that their situation may not be unique, and that the providers are familiar and experienced with the patient's problem in question.

F. Step Six: Feelings

At this point it is helpful to review the discussion and try to identify loved one's and provider's feelings and emotions. Asking self-reflecting questions such as, "Where are they in their thinking?" or "What is the ideal picture that everyone would hope for?" demonstrates that the physician is focused on the patient's desires. This important step gives the participants a chance to voice their respective wishes, which can be at times wildly unrealistic, and allows for tears and expressions of frustration or care.⁴¹ It recognizes that the conference is not a mechanistic exercise but an

³⁸ Elie Azoulay et al., *Half the Families of Intensive Care Unit Patients Experience Inadequate Communication with Physicians*, 28 CRITICAL CARE MED. 3044, 3044-49 (2000) (stating the importance of stating medical terms in lay person terms).

³⁹ See Curtis & Tonelli, *supra* note 3, at 840-41; Lautrette et al., *supra* note 11, at 476-77; Lilly & Daly, *supra* note 12, at 513-14.

⁴⁰ Tonelli, *supra* note 2, at 818 (discussing the importance of understanding the patients' values and wishes).

⁴¹ Quill et al., *supra* note 14, at 551, 553-54 (explaining the importance of allowing participants to voice their opinions).

emotionally charged, highly personal interaction. The medical provider leader can simply say, “How are you doing?” or “Do you have feelings about this?” Eliciting and acknowledging these issues extends support to those who have difficulty offering their perceptions and feelings to the group.

G. Step Seven: Options for treatment/withdrawal/care-for-comfort

Medical providers should discuss all the options that could be carried out as the final outcome. Give the pros and cons, which can also be framed as the benefits and burdens, of each option and ask the group to consider which option the patient would prefer and why.⁴² An excellent medical provider will push the group to make the reasoning for each choice explicit.⁴³ The focus should not be on CPR, for example, but all the available therapies should be discussed, both helpful and potentially harmful.⁴⁴ Allowing all stakeholders to contribute, and not just those with the loudest voice, is important. The attending nurse can outline methods of non-invasive care, such as personal care for comfort, sedatives, morphine and other palliative measures that can provide relief from pain and suffering. A palliative care consultation may be useful for general support and has recently been shown to be effective in DNR discussions with African-American families where cultural barriers may exist.⁴⁵

This is also the time to discuss all legal possibilities. If legal scenarios are introduced earlier in the conference, they tend to sidetrack the group’s focus and can dominate their respective thinking. Physicians should also be able to address the concerns of the patient who wants ‘everything’ by exploring the meaning of everything.”⁴⁶ Medical providers can do this effectively by supporting emotional responses and utilizing harm reduction strategies.⁴⁷

H. Step Eight: Leadership

The attending physician has a special duty to give a clear recommendation for one of the options discussed in a “caringly direct”

⁴² See Curtis, *supra* note 3, at 153 (discussing the importance of thoroughly explaining all the medical options).

⁴³ See Curtis, *supra* note 3, at 153 (stating that physicians should explain the pros and cons of each option).

⁴⁴ See Curtis, *supra* note 3, at 153–55.

⁴⁵ Sacco et al., *supra* note 19, at 4–5.

⁴⁶ See generally Quill et al., *supra* note 30, at 345–49 (explaining negotiation and harm reduction strategies for physicians to follow when dealing with patient and families who request that the physician “do everything” to prolong the life of the patient).

⁴⁷ Quill et al., *supra* note 30, at 347–48 (explaining negotiation and harm reduction strategies for physicians to follow when dealing with patient and families who request that the physician “do everything” to prolong the life of the patient).

manner. The recommendation should be based on data, experience, and, most importantly, knowledge of the patient's wishes. This may seem paternalistic, however, if the physician avoids the leadership role and declines to make a recommendation—effectively placing the entire burden of choice on the patient or family—the unfamiliarity, fear, and guilt may place decision making on indefinite hold which may create unnecessary delays, confusion, and suffering.⁴⁸ The physician should also discuss why he or she is making the recommendation as opposed to the other options.

I. Step Nine: Consensus and support

Medical providers should strive to reach as great of a consensus as possible. Physicians can accomplish this by summarizing the meeting and scheduling the next steps (e.g., reconvene the next day, remove the ventilator, modify the code status). Often, the patient or family need some time to process various options. Nurses and social workers at the conference have a continuing role in helping the patient and family work through the issues raised at the conference. Concluding the meeting by going around and asking those present for closing thoughts helps to build critical consensus and support.

The issue of “futile” non-beneficial treatment often arises when there is an impasse in deciding aspects of further care despite repeated discussions. Using the term “futility” with its emotional overlay and variable meaning, is not beneficial in family discussions.⁴⁹ Controversy in the medical literature exists about non-beneficial therapies: for example not offering CPR or other life sustaining treatments in a hopeless situation.⁵⁰ In Europe, the medical decision is commonly left to the doctor.⁵¹ Leaving the medical decision to

⁴⁸ Rabow et al., *supra* note 3, at 483–91; see Lamas & Rosenbaum, *supra* note 100, at 1655–57.

⁴⁹ AMA COUNCIL ON ETHICAL & JUDICIAL AFFAIRS, *Medical Futility in End-of-Life Care: Report of the Council on Ethical and Judicial Affairs*, 281 JAMA 937, 938 (1999).

⁵⁰ Compare Luce & White, *supra* note 18, at 1104 (asserting that physicians and nurses tend to pressure families to withdraw life support for critically ill families, and that this pressure can be harmful to all the parties involved, even if medically justified), with Craig D. Blinderman et al., *Time to Revise the Approach to Determining Cardiopulmonary Resuscitation Status*, 307 JAMA 917, 917–18 (2012) (asserting that the act of asking patients about CPR or the fact that CPR is the default option for cardiac arrest may bias patients/surrogates toward not choosing DNR status, even when contrary to patients' values or best interests), and Jeffrey P. Bishop et al., *Reviving the Conversation Around CPR/DNR*, 10 AM. J. BIOETHICS 61, 63, 65–66 (2010) (criticizing the U.S. practice of presumed consent/obligation to perform CPR and recommending a model more like that of the U.K., in which physicians have no obligation to provide CPR if the patient is not likely to survive).

⁵¹ John M. Luce & Francois Lemaire, *Two Transatlantic Viewpoints on an Ethical Quandary*, 163 AM. J. RESPIRATORY & CRITICAL CARE MED. 818, 820 (2001) (explaining the difference methods for medical decision making in Europe).

the doctor is more of a beneficence ethical concept than the patient autonomy approach, which is widely upheld in the United States.⁵²

Negotiations and harm reduction strategies⁵³ at times fail. In these situations an Ethics Committee consultation can be useful in resolving conflicts.⁵⁴ There are complementary similarities between patient care conferences and ethics consultations.⁵⁵ The role of the EC's recommendations may vary by the institution's policies and state law.

In general, the nurse provides the most continuity for family and patient support in the day to day care process. If there is a decision to withdraw life support, the attending nurse, social worker, and physician should discuss how to manage the care of patient and survivors alike. Monitoring equipment and intrusive tubes can often be removed. The attending physician should be present, particularly when withdrawal likely means imminent death. Involving the social worker helps with family and survivor support. The family, pastor, or others may be present, as the patient would desire, at death.

J. Step Ten: Follow through

After the patient dies, the attending physician, nurse, or social worker should make some type of contact with the patient's loved ones. Some providers attend funerals as a closure with the family, or, if they were particularly close to the patient and family, speak at memorials. Many physicians phone the spouse or loved one a few days after death, or at least send a note of condolence.⁵⁶ This allows lingering questions to be answered, and expresses human caring beyond the medical or technical environment.⁵⁷

⁵² *Id.*; Thompson et al., *supra* note 35, at 1782–83.

⁵³ *See generally* Quill et al., *supra* note 30, at 347–48 (explaining negotiation and harm reduction strategies for physicians to follow when dealing with patient and families who request that the physician “do everything” to prolong the life of the patient).

⁵⁴ *See* Lawrence J. Schneiderman et al., *Effect of Ethics Consultations on Nonbeneficial Life-Sustaining Treatments in the Intensive Care Setting: A Randomized Controlled Trial*, 290 JAMA 1166, 1170 (2003) (finding, in a randomized, prospective study of the effects of ethics consultations on the care of ICU patients, that the vast majority (87%) of involved physicians, nurses, and patients or surrogates agreed that the consultations helped to resolve treatment conflicts).

⁵⁵ *See generally* Geppert, & Shelton, *supra* note 28, at 381 (comparing medical and clinical ethics conferences); Winkler et al., *supra* note 26, at 647–51 (establishing a framework for the physician or ethics consults to discuss patient's treatment decision).

⁵⁶ Susanna E. Bedell et al., *The Doctor's Letter of Condolence*, NEW ENG. J. MED. 1162–64 (2001) (discussing the common practice of physicians after a patient's death).

⁵⁷ *Id.*

VI. CONCLUSION

Communication issues are commonly problematic when discussing EOL care options.⁵⁸ There are limitations in the bedside use of advance directives that can best be dealt with by a shared decision making process with all the parties involved.⁵⁹ Focusing on the patient's goals and values in a structured format allows for time and listening in an environment where information and feelings can be exchanged.⁶⁰ When there is an impasse and disagreement about further options for care, an EC consultation may be useful.⁶¹ A family conference guide approach is recommended for medical providers, patients, and families in order to reach difficult decisions in EOL care where there may be conflicting values.⁶² We recommend the ten step approach set forth above to successfully conduct a patient care conference for seriously ill patients.⁶³

⁵⁸ See *supra* Part II (discussing communication issues affecting end of life decisions).

⁵⁹ See *supra* note 3 and accompanying text (showing the wide acceptance of the share decision making process).

⁶⁰ See *supra* Part III (depicting the structured format for a successful patient care conference).

⁶¹ See *supra* note 54 and accompanying text (commenting on the usefulness of consultations with an Ethics Committee).

⁶² See *supra* Part III (discussing the methodology for holding a patient care conference for seriously ill patients).

⁶³ See *supra* Part III (setting forth the ten step approach).