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# PALLIATIVE CARE

Helping Patients Get the Treatment They Want **BY DAVID REYNOLDS**

**A 26-YEAR-OLD** woman is admitted with early-stage appendicitis, and the course of treatment is clear. She is immediately prepared for surgery, and the appendix is removed. The patient recovers and goes on to live a long and normal life.

A 54-year-old man suffers chest pains, and testing determines that he is suffering from coronary artery disease. Again, the course of treatment is straightforward. Since the blockage is too difficult to treat with angioplasty, the patient undergoes bypass surgery. After an extensive and somewhat difficult recovery, the patient goes on to live another 12 years before one of the grafts fails.

A 90-year-old woman with Alzheimer's disease is diagnosed with chronic kidney disease. The right treatment path—and the accompanying ethical issues—have now become more complicated.

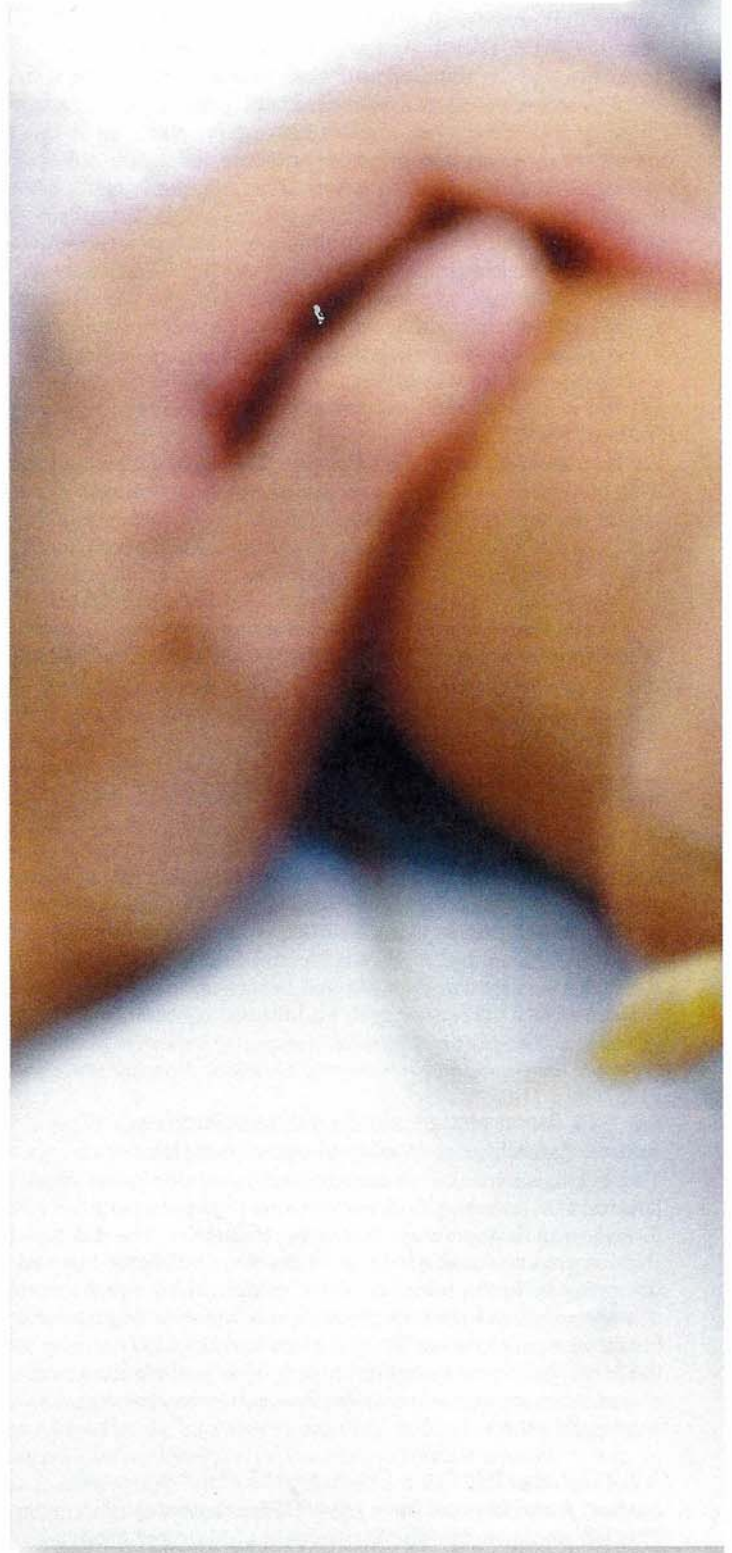
In the first two cases, physicians perform the recommended procedure. For the third, however, things aren't so clear. Is the woman a candidate for a transplant? Should she go through dialysis? Who makes those decisions? And, if neither transplant nor dialysis is appropriate, what should be done for this patient? What's right for the disease may not be right for the patient.

The answers to these dilemmas—at least partially—may lie in the expanding field of palliative care, which focuses on relieving suffering and improving a patient's quality of life by addressing a disease's symptoms, rather than on trying to cure or delay the disease itself. Palliative care, along with a deliberate understanding of a patient's needs and values (through such mechanisms as the POLST Paradigm and conversations between physicians and patients), may offer some guidance.

## Ethical Considerations

**ALTHOUGH PALLIATIVE** care is most often associated with end-of-life or hospice care, it has recently taken on its own identity beyond that—those who choose it are more diverse. Palliative care is medical care that focuses on treating a patient's symptoms, rather than focusing on curing or even delaying the advancement of the patient's disease. The philosophy behind palliative care is to provide the best quality of life for a patient, regardless of diagnosis. Patients who choose palliative care include:

- Those facing end-of-life
- Those suffering chronic, non-curable conditions that cause



- distress, pain or suffering
- Those undergoing curative treatments with distressing side effects
- Those who need pain spiritual and psychological care to deal with an illness
- Those who need help addressing a broader support system, including family, for an acute illness

But patients confronting terminal illnesses must face the difficult question of how they want to die, and in doing so, must address—with the help of their physician—how to manage their pain, discomfort, and symptoms. And that’s one of the first ethical issues that many physicians face: separating consideration of the disease from consideration of the patient.

Figuring out what’s right for the disease is often straightforward, but in the larger context of what’s right for the patient, it becomes more complex. Tarek Mahdi, MD, medical director of the Inland Empire Palliative Care Coalition, offers some perspective. “Being aggressive isn’t always the right thing for the patient,” he says. “It might be the right thing for the disease itself, but it might not be the right thing for the patient. We always have to make sure it’s the right thing for the patient.”

As an example of this ethical issue, Dr. Mahdi cites the hypothetical case of a patient in her late 90’s who comes in with blocked coronary arteries—and who is also suffering from advanced Alzheimer’s. In this case, the right procedure for the disease might be CABG surgery, but when looked at in the larger context of the patient’s current health situation, values and wishes, as well as what the patient’s family has to say, what’s right for the patient might be very different.

Complicating this situation in many cases is when patients cannot speak for themselves, which is when many physicians run into another ethical consideration—what treatment course to follow without being able to ask the patient. A physician will consider their previous relationship with the patient (if any), talk to family members (who may be conflicted or simply not know what the patient may want), and consult any records or documented patient wishes (if the patient has filled out a Physician Orders for Life Sustaining Treatment form or has a medical directive). One thing that can help physicians, patients, and families all navigate these issues is having a clear understanding of a patient’s wishes and values, and understanding those in terms of what that patient’s family needs and wants.

### Having the Conversation

**ACCORDING TO DR. MAHDI**, discussing a patient’s wishes is becoming increasingly important as people live longer. “Thirty or forty

## 6 Tips for Talking about Palliative Care

**IT’S CERTAINLY** not comfortable to discuss end of life options but studies show that the patients are better off for it. Here are six tips for making the conversation easier to have with your patient or their family.

- Since most patients expect physicians to broach the topic of palliative and end-of-life care, be prepared to take the lead.
- Although discussions will likely include discussion of resuscitation options, talking about palliative care often covers much broader topics. Be open and direct when discussing these.
- Make sure family members are involved in your patient’s palliative care discussions.
- Use open-ended, probing questions to get at your patient’s needs and values.
- Prepare to have more than one discussion—understanding your patient’s wishes takes time.
- Remember that providing palliative care does not equal to medical failure.

years ago, when life expectancies were lower, we didn’t have to look at these issues because we just died,” says Dr. Mahdi. But now, we’re living into our 80’s and 90’s, and people aren’t dying in the same way as before. More often, people face prolonged and painful illnesses as they age. And when patients can’t speak for themselves, the challenge is even greater, which emphasizes the need to know what the patient needs and wants before the situation arises. That’s when it’s time to open the conversation.

“My elderly patients all want to have that discussion,” Dr. Mahdi says. “I’m 55 and I start to think about it. There is a time limit for all of us, and as we age, we start to think more about the time when it comes. I can’t imagine a 90 year old that’s not thinking about death and how it’s going to happen. Is it going to be comfortable?”

Studies show that patients want to discuss end-of-life and palliative care, and physicians think it’s important, Dr. Mahdi notes, but in reality, few discuss it. Indeed, national guidelines recommend discussions of end-of-life issues when patients have limited time left so that patients’ preferences can be met. Some evidence suggests that when these discussions occur, individuals have better experiences with death.

Yet, a study by Nancy Keating, MD, of the Brigham and Women’s Hospital and Harvard Medical School in Boston and colleagues, which was published on January 11 of this year in the journal *Cancer* underlines physicians’ reluctance to talk about end-of-life and palliative care.

In a survey of over 4000 physicians, the study authors asked how they would talk to patients at end-of-life (four to six months left to live). Some 65 percent said they would discuss the patients’ prognosis, while 44 percent said they would talk about do-not-resuscitate orders. And only 26 percent would discuss hospice options, while 21 percent said they would talk about where the patient wanted to die. Physicians responded that they would prefer to wait until they were out of treatments or until symptoms were present to begin a discussion.

The survey also found that younger physicians and physicians who were not cancer specialists would discuss end-of-life options sooner than older doctors and cancer specialists. Physicians caring for patients in HMO or VA settings were also more likely to start these discussions earlier than physicians who cared for patients in other settings.

Physicians surveyed gave several reasons for delaying a discussion about palliative care including:

- avoiding crushing a patient’s hope
- wanting to continue treatment
- understanding that patients don’t want to discuss the topics.

- distress, pain or suffering
- Those undergoing curative treatments with distressing side effects
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- understanding that patients don't want to discuss the topics.

One reason why these conversations aren't held is very simply that they are uncomfortable. "Having those conversations is uncomfortable," says Jackie Kimball, Palliative Care Coordinator at St. Bernadine Medical Center in San Bernadino. "People want to stick with what's comfortable, and so the conversations may not always be productive."

But both Dr. Mahdi and Kimball agree that there are other reasons, including one that requires a shift in perspective. "Death and dying is considered a failure," Dr. Mahdi says. "We need to think about it differently. People do die." Adds Kimball, "Physicians are trained to save people. This does not feel like a success to them. They don't like talking about it more than is necessary."

Although Kimball says a few families will come to them to discuss palliative care, more often, someone on staff recognizes that a palliative care conversation may be appropriate. And if a patient and a physician are communicating, then a palliative consult isn't always necessary.

Kimball notes that gaining a true understanding of a patient's wishes when it comes to pain relief and treatment paths is more than a single conversation. "It's a series of discussions," she said. "It's not one. The first one only says 'things aren't looking good.'" And once the conversation has been broached, physicians can discover what their patient wants in terms of treatment and pain relief.

Key to this conversation is the families and caregivers. These people are critical to providing a patient with high-quality palliative care, especially in end-of-life situations. The physical and emotional toll on these people, however, is often tremendous. And so, approaching family and caregivers with palliative care and end-of-life discussions may require a shift in perspective. How they're approached is key. "They never forget," Kimball says. "It is a sacred time. People do not want to make a mistake. So it's a whole different thought process than medical decision making."

One other reason for reluctance to discuss palliative and end-

**"Dr. Mahdi believes that physicians often avoid palliative care discussions because death and dying is considered a failure. He states, 'We need to think differently about it. People do die. Physicians are trained to save people. This does not feel like a success to them. They don't like talking about it more than is necessary.'"**

of-life care may include the larger view of a patient's situation, given how emotionally charged these situations can be. "We don't receive a great deal of training on spiritual and emotional crises," Kimball notes. "It's not just medical decision making. It breaches medical, spiritual, and so on."

Other than helping physicians understand patient needs and consequently make the right choices, having conversations about palliative and end-of-life care can help patients make more informed decisions. In a January 10, 2010 study in the *Journal of Clinical Oncology*, patients who watched a six-minute video on palliative and hospital care, and lifesaving procedures dramatically changed their care choices. The 23 brain cancer patients who saw the video chose palliative-style care aimed at comfort over hospital and life-extending care at a rate of 91 percent. For the 25 brain cancer patients in the study who were told about the same topics but did not watch the video, only 22 percent made the palliative-style care choice over hospital and life extending care.

And if you are concerned about legal risks when it comes to discussing palliative care and end-of-life issues, then follow the advice of Devin O'Brien, Senior Council and Managing Attorney for medical liability insurance provider The Doctors Company. It boils down to two key items. First, physicians should talk multiple times with their patients about their treatment wishes at end-of-life, and those conversations should be had in the presence of family members. Second, the results of these conversations should be well documented—in addition to completing the Advance Health Care Directive and POLST forms. This minimizes any surprises, helps family members prepare for transitions, and makes sure that there's a record of what was discussed.

## A History of Palliative Care

**PALLIATIVE CARE'S** roots go back as far as the first time that people began caring for the sick and dying—and until recently, the two were often tightly intertwined. Until the 19th century, providing end-of-life care (including some of the palliative care principles) was something that was typically done by the family or by the church—not by medical professionals.

But over the next 200 years, end-of-life care shifted from the home to hospitals

and care facilities. And with the psychosocial groundwork regarding death and dying being laid in the middle of the 20th century, medical professionals begin to make scheduled pain treatment a regular part of hospice and palliative care. At around the same time, increased attention is paid to the suffering as well as psychological and social needs of patients and families.

In 1984, hospice was added as a Medicare benefit, and by the turn of the millennium,

over 3000 palliative care programs were active in the United States. The World Health Organization prioritizes palliative care and publishes a set of palliative care standards.

Originally, the American Board of Hospice and Palliative Medicine provided board certification for palliative care, but this has changed to include any of 11 specialty boards by using an American Board of Hospice and Palliative Medicine procedure.

**“Having the patient’s wishes recorded is especially important when a patient cannot speak for his or her self. Patients should consider having both a POLST form and an Advance Health Care Directive. While both express the patient’s wishes, they do it in different ways. POLST contains physician’s orders; an Advance Health Care Directive does not.”**

Despite any legal concerns, O’Brien stresses the importance of solid end-of-life care. “Palliative care should be part of any physician’s armament,” O’Brien said. “In this day and age, it would be unreasonable to not have this as an option to an appropriate patient.”

### Recording the Patients’ Wishes

**HAVING THESE** conversations is important, but if a patient changes physicians (due to insurance changes, relocation, or other factors), all that hard work is lost. “If a physician is lucky enough to have a long-term relationship with a patient and gets to understand that patient’s needs and long-term values, that’s great,” Dr. Mahdi says. The problem, he notes, comes when the patient has to move to another physician due to insurance changes or other issues. When that happens, the medical record gets transferred, but the results of that conversation do not.

That is, unless steps are taken to make sure that a patient’s wishes and values are recorded. That’s where mechanisms such as the Physician Orders for Life-Sustaining Treatment (or POLST) come in. This brightly colored form records a patient’s wishes regarding life-sustaining treatment with the force of a physician’s orders. And this form stays with the patient, helping to ensure that his or her wishes regarding end-of-life care are followed. Having a copy of the patient’s POLST posted next to his or her bed (in addition to having it as part of the patient’s medical record) helps ensure that the patient’s wishes are followed.

life-sustaining treatment under AB 3000, effective January 1, 2009. Physicians and patients are not required to fill out a POLST form, but if one is filled out, California law requires that the physician orders in a POLST must be followed by health care providers.

These days, POLST has grown to play a very important role in shaping end-of-life care. Says Dr. Mahdi, “POLST helps carry the conversation with the patient as part of the medical record. It serves as a start for making sure that a patient’s wishes get transferred.”

Having the patient’s wishes recorded is especially important when a patient cannot speak for his or herself, Kimball says. POLST is not the only way for patients to accomplish that. A patient can also complete an Advance Health Care Directive, which can provide both instructions for health care, as well as appoint an agent with power of attorney for health care decisions. POLST contains physician’s orders; an Advance Health Care Directive does not. Physicians can help their patients understand how the two forms work together to provide a more complete picture of a patient’s wishes and values when it comes medical care at end of life.

Patients should consider having both a POLST form and an Advance Health Care Directive for a couple of reasons. While both express the patient’s wishes, they do it in different ways. Although the Advance Health Care Directive allows patients to be as specific as they like, often the form is filled out with just basic information. Besides being specifically designed to be easy to find in case of emergency, POLST also expresses the patient’s

POLST started in Oregon in 1991 when representatives from various health care organizations met in conjunction with the Center for Ethics in Health Care at Oregon Health and Science University. Their goal: to develop medical orders covering life-sustaining treatments that would move with a patient. The POLST Paradigm expanded to other states, including California, where it became part of California law regarding

## 5 Things You Should Know About Palliative Care

**EVEN IF** you may never have a patient in need of palliative care, you should understand the basics about what palliative care is—and what it is not. Here are the five main things you should know no matter what your specialty.

- Palliative care isn’t the same as hospice care, although the two are very often intertwined;
- Palliative care can be brought in much earlier than hospice care, which generally does not begin until about six months from end-of-life;
- A Physician’s Orders for Life-Sustaining Treatment form is important to have to ensure that patients’ wishes are expressed and followed, especially in the event that they cannot speak for themselves;
- Two common ethical issues include how to make decisions when a patient cannot express his or her self, and when the right treatment for the disease isn’t necessarily the right treatment for the patient.
- Having conversations regarding palliative care can be difficult and uncomfortable, but those conversations are very important. Studies show that patients want to have these conversations and often benefit from them.

wishes through doctor's orders.

### Palliative Care and End of Life

**PALLIATIVE CARE** is about more than treating patients at the ends of their lives. It's also about symptom management, comfort, and matching patient goals to the treatment they receive—and more and more, palliative care is about managing chronic conditions and symptoms, and it may have nothing to do with end-of-life care. Kimball estimates that a third to a half of the cases that her group consults on “are about managing a non-curable illness that's nowhere near terminal, such as diabetes and heart disease.”

She notes that although hospice care and palliative care often go together, there are some significant differences. Hospice care is typically given during the last six months of life, where a patient has determined that hospital care has nothing more to offer and that he or she would rather receive end-of-life care at home. “Palliative care does not do that,” Kimball said. “It can be brought on much earlier, and we do not recommend that folks forego aggressive and curative care.”

But when palliative care and end-of-life care intersect, it can bring out the very best in caregivers—and it can also offer the most challenge. “We're very passionate about giving patients the best care we can at the end of their life,” Dr. Mahdi says. “That's where the art of medicine takes place. There are lot of possibilities, and it helps us look at the humane things. It's a very individualized patient and family decision.” ■

## Of Interest

**IN THE U.S.**, palliative care services are generally paid for by fee-for-service, direct hospital support while Medicare is paying for hospice care, or by medical care philanthropy. Medicaid and many private health insurance plans offer similar benefits tied to hospice care.

Palliative care is available to any patient regardless of prognosis, but when considering the Medicare Hospice Benefit, two physicians have to certify that the patient has less than six months to live if the patient's disease follows the usual course.

### Hospital-based palliative care in California

According to a review published in 2008 by the California HealthCare Foundation in conjunction with the National Health Foundation and University of California, San Francisco, Palliative Care Team, 43 percent of hospitals responding have a palliative care program. Also of interest:

- 90 percent of palliative care programs were launched in the previous eight years;
- Nonprofit facilities were most likely to have a program;
- 57 percent of teaching hospitals have programs to incorporate palliative care in their instruction for new physicians



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