



EDITOR'S NOTE: Portions of this article are adapted from Kathleen Benton's book, *The Skill of End-of-Life Communication for Clinicians*.

Listen with Compassion, Trust the Patient

KATHLEEN BENTON, DrPH

Daniel, a 30-year-old man with Proteus syndrome (“elephant man disease”), was my brother. After 110 surgeries and complications of disease and treatment, our family elected to care for him at home in the final stages of his life. We promised him that we would give him our support for as long as he needed us, and we did.

What he refused to acknowledge was the strength he gave to those around him. Daniel defined dignity of life. Some days, Daniel was angry with me for even saying he was sick, and some days he shared privately with my mother that he knew he was dying. It depended on what he wished to believe in a given moment, and how OK he felt with it. And when he did die, it was just as it should be. He went into respiratory distress, asked for an ambulance to the hospital where he was put through resuscitation and shock, just as he wanted.

Was that “futile care”? Not for Daniel. It gave him exactly what he wanted: last minutes with my parents. They were called to his bedside, and they both got to tell him they “would be OK,” and he could go and enjoy his peace, his eternal party.

At that moment, he left, with a tear running down his cheek and a smile on his face.

At that moment, he taught us that some aggressive care has its purpose, in the patient's phase of death.

We must trust our patients.

END IS A PHASE

Daniel taught me an invaluable lesson, as he always indirectly did: End of life is a phase for many patients in this age of technology and

advancements. It is not necessarily a moment, or an imminent week, or a day. It may take place over years of a patient's life. But it is a phase.

As professionals, that concept challenges us all the more to prepare those anticipating grief. We must offer hope of time together within the reality that the disease is final. The critically chronically ill — and their families — deserve to understand their outcome and make their choices for living to the fullest in the meantime. With Daniel in mind — as he always is for me — I recommend staunch advocacy and constant conversation during the end-of-life phase. I also would encourage each health care professional and family member to ask and answer the uncomfortable questions when it seems clear there is too much unknown and unsaid.

PROFESSIONAL-TO-PROFESSIONAL COMMUNICATION

Ego or intimidation compromises basic communication. I am speaking of the conversation, or lack of it, that occurs among providers or between the care team and the provider. It is crucial that we all talk with each other. Even after years of seeing these dilemmas, it shocks me to find out that two consulting physicians have relied only on notes in the medical record to “communicate” with each other — and sometimes they haven't even read

the notes completely. We all have cell phones. We tend to guard those numbers, but you should be reachable by your fellow providers. I can only advocate for the skill and approachability of the simple sentence “Please call my cell phone to discuss [patient] further or for any questions,” and then provide the number. It is that easy.

The more obvious disconnect in professional-to-professional communication is between the provider and the support staff. Frequently, allied professionals (nurses, respiratory therapists, physical therapists, nutritionists, speech therapists, social workers and so on) avoid contact and direct communication with the physician/provider because of inherited and learned hierarchal standards — or authoritarian intimidation.

Is that you? But you have important information to communicate, because you are:

- The nurse who sits at bedside and learns every detail about the patient

- The social worker who knows more about discharge planning and legal documents than other staff

- The respiratory therapist who likely knows better how to intubate/extubate/take off paralytics and what to expect each time

- The speech therapist who makes recommendations to allow/disallow eating. You are aware that the 92-year-old, demented patient is likely to pull the tube

- The physical therapist who knows whether a rehabilitation order is written in vain because the patient will not rehabilitate physically

- The nutritionist who knows diet better than any other health care worker

Without your information, there is too much space for medical error and lost time in a patient’s end-of-life phase. Write candidly and without discretion in your notes, and go beyond your notes — figure that some of your notes are never read. When you have a concern, reach out, speak to the provider, and ask. If you notice that their notes are more candid than what they relay to the patient, read their notes to the patient or surrogate.

I am not alone, either personally or professionally, in seeing the need for improved communication at this time of a patient’s life. In the published brief *Dying in America*,¹ the Institute of Medicine recommended better professional education to

correct “deficits in equipping physicians with sufficient communication skills.”

RESPONSIBILITY OF ALL

Kudos to members of the palliative care specialty, with all they have brought to the conversational table. But it should not be left up to a single discipline with a shortage of providers to make believers of those who do not see the worth of the end-of-life conversation. Nor is it fair to expect them to further educate people who align the palliative specialty with hospice.

Other experts, specialists and clinicians need to know how to talk to dying patients, their families and caregivers, and those professionals must be held accountable so that they don’t put off or avoid uncomfortable conversations.

Frequently, allied professionals (nurses, respiratory therapists, physical therapists, nutritionists, speech therapists, social workers and so on) avoid contact and direct communication with the physician/provider because of inherited and learned hierarchal standards — or authoritarian intimidation.

It is too easy to visit less when a patient is progressively sicker, or to drop by with news of good lab numbers or successful oxygen stats that do not actually represent the overall state of a dying patient. All specialists should relay, with compassion and truth, the big picture of prognosis. Otherwise, to put it bluntly, they are stealing moments from patients and their loved ones at the end of life, a time better spent by easing grief with found closure, strengthened faith and achievement of last goals.

The Joint Commission cites lack of communication as an aligning factor to safety deficits, and it recommends health care organizations support and train clinicians to conduct advance care planning, in order to ensure that the planning is what matters to the patient and that the dignity of



C. PANNELL

HOW TO HOLD CONVERSATIONS ABOUT THE END OF LIFE

Here are some guidelines for conversations about the end of life:¹

■ **Timing.** If your attempt follows several failed attempts to halfheartedly declare the end is near, you will be drowned out by those who came before you. Best to wait and begin rapport, define yourself as someone different at that point. This might mean waiting a day, just to give the patient a break from the end talk. If an event has occurred with another hospital or opinion that has created an air of distrust in all health care, give the patient time to process what has been explained. This internal processing time for the family may increase the length of time it takes for them to come to trust you. They must address and resolve the issues causing their earlier distrust before any discussion with you is worthwhile. The conversation is lost in emergency situations as well, since the family will be frantic and the patient usually is uninvolved at this point.

However, for a family that is unwilling to consider a Do Not Resuscitate order, witnessing their loved one's code may be a good time to readdress this situation. The answer is in the process, not the pressure. Likewise, you may be there. You may see the futility and wish the family could see it as well. What makes this process so difficult is the journey they were on before they met you. Unless very progressive doctors took them by the hand early, they have likely heard next steps, next treatments, how things will be fixed and what aggressive escalation is recommended. Then all of sudden — from their point of view — there is no recommendation but the withdrawal of everything, every treatment they signed consent to. That understanding does not happen easily. And likewise, leaving too much time to follow through with an end-of-life plan is not a good tactic. Time kills decisions.

■ **Sit down.** It's been written before, and it is no joke. Being at the patient's eye level or below is key. Frequently when I cannot locate a chair in a crowded hospital room, I sit on the bed with the

patient, or I squat down. I do not want any intimidation to be conveyed through my body language. They need to think clearly so questions can be asked and answered. All too often in health care, the patient is spoken over, not with.

■ **Listen.** Try to gather details about the family and the dynamics you are stepping into. That information can be useful for choosing your strategy of explanation. It also might help build instant rapport with the family to know something of their psychosocial situation. For example, "I understand you have been caring for Mom for 11 years; she is lucky to have such a good daughter."

Be motivated to listen. It will save time to *take* time. It is unnecessary to walk into the room while looking at the chart; leave that to the doctors on television. Such an action immediately disconnects the patient or surrogate from your expertise.

When you enter the room, some of the best conversations begin: "Hi, Ms. Smith, I am Dr. Benton, Kathleen Benton. Before I start talking, I would like to understand what you are thinking. Tell me what you understand about your illness" (or your mother's illness, if you are talking to a surrogate). Be an active listener and try not focus on making notes, other than jotting down disconnects that you need to clear up *after* the patient or family member finishes talking. This kind of very simple and direct communication may eliminate weeks of frustrated discussion.

■ **Specialist, do not speak only in terms of "your" organ.** You are a well-trained professional. Despite your expertise in that one area, you should know that talking about improved kidney function in a metastatic patient does not equal "things are better." Many patients and their families are confused by positive information about the recovery of one organ when many of the others are dwindling. It is misleading and inaccurate.

Give a big picture, something like: "She is very weak today. Even with her kidney numbers recovering, we know the

cancer continues to weaken her, and she cannot live on kidneys alone. We need to look at the whole body."

■ **Simplicity is in the semantics.** Using your patient's and family's names and attempting to hold on to that information will help your communication. We take medical terminology for granted; people who have not worked in medicine can find it challenging and sometimes frightening. So as you speak, change "DNR" or "Do Not Resuscitate" to "allow natural death," replace words like "vent" or "respirator" with the term "life support." Make reference to all organs by words the patient understands: not pulmonary, but lung; not renal, but kidney; not cardiac, but heart. When only one person understands what is being said, it is not a conversation — it is a lecture.

Some of the most challenging semantics involve imminent death. Phrases like "nothing we can do" or "not much else to add" are conversation breakers. There is always something to do or add in terms of offering comfort or discussing an individual's legacy. You must be truthful about an outcome, but don't break the conversation and stop listening.

■ **What to say is just as important as what not to say.** If you have difficulty, practice saying some of these aloud:

Use the phrase "**at end of life**," followed by quickly explaining this could mean days or months.

Use the word "**dying**," because if the patient is dying, it needs to be said.

Ask "**What can I do to support you?**" The patient and/or family is experiencing anticipatory grief. Be their ally and recognize their devastation.

You aren't bound by the four walls of the hospice or home, so if you feel called to, reach out, send flowers or bring food.

NOTE

1. Kathleen Benton, *The Skill of End-of-Life Communication for Clinicians* (New York: Springer, 2017), 61-62.



the patient is maintained and respected. Recommending or proceeding with procedures or treatments that are not consistent with what matters to the patient is a patient safety issue that could lead to harm and sentinel events.²

But one of the most difficult challenges for professionals is to identify when is the right time for end-of-life conversation and planning. Should it be when death is imminent in the ED? Should it occur in outpatient primary care offices early in disease? Should specialists learn how and when to communicate prior to a recommended procedure?

To my mind, discussions and planning should begin with a conversation in the primary setting, then continue and evolve as a patient's medical circumstances change. The conversations and plans should take into consideration treatment options, possible complications and be based on clear understanding of the patient's condition. It is not enough to advise a patient to complete an advance directive form and stop there — all clinicians and health care workers should lead the way in initiating and continuing the conversation.

BEGIN CONVERSATION EARLY

When a patient might live a little longer with a tracheostomy, might make it to nursing home admission, or might get off the vent, we are more likely to talk about the procedure rather than the end of life. However, even if the patient does improve, the end of life might still be near — and the patient and family need and deserve to know that so they can make informed choices.

A change of perspective would help as a first step. Hopefully, end of life is a phase, not just one scene. Daniel's end of life was ongoing and lasted years. Technology and advancements allow this, though even without artificial support, end of life can last an extended period of time. Why is this important? Because it gives the providers and supportive team the permission to start talking about it early.

Physicians have to be able to recognize when diagnoses are adding up to a patient's last phase. Only the will and spirit of the patient will define when it is imminent, but as a rule of thumb, if the patient is admitted to the hospital and on artificial support, the conversation is a must.

However, even when the patient under your care is not in the hospital, if he or she is diagnosed with a serious, eventually terminal illness, the

best scenario is to begin the conversation then.

Death is inevitable, whether we meet it in a hospital, at home, on the streets or in the wilderness. It is the great unknown. Some patients will ease into death, and some will fight it as if it is a battle they always have prepared for. My brother, among the latter group, was not an enigma nor an anomaly, he was a certain type. I have learned that you do not ignore types.

Some consider death in a hospital sterile and uncomfortable, yet the vast majority of us die there anyway. For those patients who choose to die at home, their wishes must be made known to their family and members of their treatment team.

In truth, it can take many, many explanations for a patient and family to recognize and process the fact that allowing a natural death at home, instead of in a code at the hospital, may mean letting go. You meet them where they are and sit with them. You embrace their culture and faith rituals at the end.

Oftentimes by acting through compassion, you may open the door to discussion. It could be an impending, other issue that is inhibiting acceptance of the end stage. It may seem not your job to listen to and address that other concern — financial, relational — but it may be the most important step you take as a mission-focused health care provider.

You listen, above all else, and do not abandon. Some will die in denial, some with clear focus on the path ahead. All should die in hope of something better. For all we know about life, living and eventually dying, what comes next is the biggest mystery of all.

KATHLEEN BENTON is director, clinical ethics, St. Joseph's/Candler Hospital Campus, Savannah, Georgia. She is the author of *The Skill of End-of-Life Communication for Clinicians: Getting to the Root of the Ethical Dilemma*, published in July 2017 and reviewed in this issue of *Health Progress*.

NOTES

1. Institute of Medicine, *Dying in America: Improving Quality and Honoring Individual Preference near the End of Life* (Washington, D.C.: National Academies Press, 2015).
2. The Joint Commission, "End of Life Care, a Patient Safety Issue," *Quick Safety* 15 (July 2015).

JOURNAL OF THE CATHOLIC HEALTH ASSOCIATION OF THE UNITED STATES

www.chausa.org

HEALTH PROGRESS®

Reprinted from *Health Progress*, November - December 2017
Copyright © 2017 by The Catholic Health Association of the United States
