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
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.

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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
**HOW TO HOLD CONVERSATIONS ABOUT THE END OF LIFE**

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

- **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 understand about your illness” (or your mother’s illness, if you are talking to a surrogate). Be an active listener and try not to 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 direct communication may eliminate weeks of frustrated discussion.

- **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 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**

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 though 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.

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