



A Guide to Discussing End-of-Life Care Options with Your Patients

“I wish we had known about hospice sooner.”

Most hospice clinicians, volunteers, and care team members will tell you this is the number one comment they hear from patients and their families.

Hospice care focuses on the quality of life for patients and their caregivers experiencing a life-limiting illness or condition. A team of trained hospice care professionals works to manage symptoms and meet the patient’s physical, emotional, and spiritual needs. Although hospice care is meant for patients nearing the end of life, it does not hasten death. The goal is to allow the patient to live to as long as possible, as comfortably as possible. In fact, there is evidence to support that [hospice patients may live up to 29 days longer](#) than their non-hospice counterparts with similar diagnoses.

Despite the proven benefits of hospice care, less than half of terminally ill patients are enrolled in hospice, and those who do enroll generally do so very late in the course of their illness. Among the 1.5 million Americans who received hospice services in 2018, [40% percent were served 14 days or less](#) – just a fraction of the 180 days of hospice care Medicare will cover.

Timely hospice referrals are a critical factor for patients with a terminal prognosis. When patients and their families do not access these services in a timely manner, they do not receive the full benefit of hospice care. [Evidence shows](#) that patients referred to hospice less than one week before their date of death received fewer benefits of hospice in terms of symptom management, emotional and spiritual support, and nursing care. In contrast, patients and families who received hospice care for 30 days or more reported the most benefits of hospice.

There are many obstacles in transitioning a patient to hospice care. Sometimes patients with a life-limiting condition and their families are unreceptive to hospice care, either due to a lack of knowledge about what hospice truly is or a desire to continue curative treatment.

However, one of the biggest obstacles to a hospice referral is that physicians are often unsure how to talk to their patients clearly and honestly about their poor prognosis and limited treatment options. While [90% of physicians](#) report being aware of hospice, one-quarter said they do not address hospice options with their terminally ill patients, and the other three-quarters report discussing hospice “selectively.”

It’s not surprising that many physicians find it challenging to engage in end-of-life discussions. Physicians are trained to preserve health and combat illness and often lack guidance on communicating with dying patients and their families about hospice care.

When done correctly, discussions about end-of-life care can bolster doctor-patient relationships and increase the likelihood that patients will choose appropriate treatment options. Good communication can help alleviate fears, minimize pain, and allow patients and their families to experience a “peaceful death.” On the other hand, poor communication can result in suboptimal care and unnecessary mental, physical, and emotional anguish.



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This resource will help you foster a comfortable, more productive dialogue with your patients and their families about end-of-life options and hospice care.

When to Start a Dialogue About End-of-Life Care

The hospice talk is difficult but necessary, and timeliness matters. Although these conversations are tough on all parties, studies show that [patients want to discuss end-of-life care](#) with their physician, and the majority think [physicians should introduce the topic](#).

It's best to begin discussing end-of-life options with the patient early on – even at the time of the initial diagnosis, if possible. Early discussions on this topic provide the opportunity to elicit the patient's overall thoughts about end-of-life care. Talking about end-of-life care early and candidly makes the idea easier to digest and ultimately enables the patient to make an informed choice. It can be incorporated with a more extensive discussion about the patient's goals of care as you create a treatment plan.

“We can't predict exactly what kind of medical treatment you may need at the end of your life, should your disease progress to a terminal stage. I need to know your thoughts about what type of medical care you would like to receive in that situation. How do you want to spend your last days, weeks, and months?”

Additional probing questions may be necessary to clarify the patient's end-of-life wishes. Don't be afraid to go a bit deeper with them.

“You said that you don't want to suffer. What type of suffering do you want to avoid?”

“You said that you don't want to be a burden to your family. What would you consider to be a burden?”

While you can elicit the patient's general thoughts about end-of-life care in these initial discussions, the first conversation should not be the last. Your patients' preferences may change over time, and they may not. Discussing hypothetical scenarios early on is an effective way to initiate end-of-life discussions, but necessary decisions must be made as the situation arises. That's why maintaining open communication is key to allowing physicians, patients, and families to respond to changing medical and psychosocial needs.

The preferences of terminally ill patients trend toward less aggressive care as their illnesses progress. Most patients believe that, at some point, life-prolonging interventions should be limited. We can support this important notion by asking:

“Are there any treatments that you might not want to receive? Are there any circumstances in which you believe life-prolonging treatment would not be desirable?”

A supportive physician-patient relationship provides a crucial foundation for end-of-life care. Patients and families speak more openly and are more trusting when they feel their doctor's empathy and compassion.



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How to Talk to Your Patients About End-of-Life Care

There is a natural tendency to downplay bad news – even the seriousness of a patient’s condition. When no viable therapeutic options remain, it’s critical to acknowledge this with directness and compassion. There must be no chance for misinterpretation. When terminal patients are not fully aware of their prognosis, they tend to overestimate their survival, influencing their preferences regarding medical treatment.

"The treatments that helped you in the past are no longer working, and your condition is getting worse. Most people at this stage of the disease can expect to live another 6-12 months. But that is the average patient, and I cannot predict precisely how you will fair. I certainly hope that you will do better than average, but it is also possible that you may do worse."

Patients and families may need repeated explanations to comprehend fully. As with all medical discussions, use straightforward language and avoid technical wording. During times of high anxiety, concentration and comprehension may be limited. It may be helpful to ask:

"I want to be sure that I have clearly explained your medical situation. Can you give me your understanding of what is ahead for you?"

It’s important to remember that although physicians attend the experience of death many times, a family goes through it only once with a loved one. Patients and families need time to reflect, to feel confident they are making the best choices. During this challenging time, patients and families may harbor seemingly irrational hopes for an improbable reversal. Supportive, unpressured discussions increase the likelihood that sensible and humane decisions are ultimately made.

Once a patient and family acknowledge that death is approaching, the physician’s role is to facilitate an open discussion about desired medical care and remaining life goals.

"As your doctor, I want to ensure we never do anything that either can't help you or you wouldn't want. So, I need to know what things are most important to you, given your illness. How do you want to spend your remaining time?"

As death nears, most patients share similar goals: maximize time with family and friends, avoid hospitalization and unnecessary procedures, maintain functionality, and minimize pain. Earlier discussions about general desires need to be revisited, as the immediacy of a worsening illness may modify one’s feelings and thoughts.

"A few months ago, we spoke about what kind of care you would want if you became very ill, and you said you wanted to be admitted to hospice care. We're now facing that situation. I want to know if your thoughts are the same or if they have changed in any way."

Providing quality end-of-life care requires understanding how patients and families experience the dying process and a sensitive communication style. With these skills, physicians can conduct thoughtful discussions in which most decisions evolve comfortably.



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Caring for a dying patient is not easy, but it can be a meaningful and gratifying experience for the physician. To help someone die in comfort, in peace, and with dignity is to give one final gift of life.

When you refer a patient to Intrepid USA Hospice, our team can help you discuss hospice care with your patient and their loved ones. Contact your [local Intrepid USA Hospice Care Center](#) today, or fill out the [Refer A Patient](#) page on our website.