

Talking with Patients About Hospice

How comfortable are you discussing end-of-life care with your patients?

Research has shown that although terminally ill patients and their caregivers are comfortable talking about end-of-life care, they prefer that providers initiate the discussion. These patients have relied on their providers for guidance throughout their illness, and they are looking for advice about end-of-life care too.

But talking about hospice can be daunting for everyone involved. Although your patients and their families likely want to have peace and comfort at the end of life, they might also be holding out hope for a cure (or more time) and be reluctant to stop curative care. And even when you understand the value that hospice care can bring to your patients, you may be hesitant to talk about it. Yet according to a [2017 KFF report](#) on end-of-life views and experiences, 88% of Americans would prefer their provider to be completely honest in the face of a terminal illness, and only 7% want their provider to emphasize hope instead.

This is why it is critical for providers to take the lead when it comes to discussing end-of-life care.

Here are ways you can make the conversation easier for everyone involved and ensure that your patients can make informed decisions about hospice care.

Start the End-of-Life Conversation Early

Despite the potential for discomfort, the conversation about end-of-life care is a necessary one. It's also one to start early — as soon as you know that your patient's prognosis is terminal and that they probably have only a few years left to live.

Starting early also allows you to discuss multiple aspects of end-of-life care, not just hospice. Ask your patient questions such as:

- What do you value most in your life? (This could include spending time with family or being able to participate in certain activities.)

- Given your current health status, what are your priorities? What is most important to you? (As their status changes, revisit this question.)
- If [situation relevant to their condition] occurs, what would you want to do?
- If you are unable to make decisions about your care, who would you like to make those decisions for you?

Starting end-of-life care discussions early establishes [advance care planning](#)* as part of their care and can make the topic less daunting in the future. It may also give patients and their families time to come to terms with their diagnosis, so that when hospice care becomes appropriate, they are ready to accept it.

Educate Your Patients About Hospice

Although most Americans have heard the word “hospice,” not everyone fully understands it.

[A 2021 study](#) on perceptions of end-of-life care found that among a sample of more than 9,800 adults in the United States, 83–85% were aware of hospice, but 37% had misconceptions about it. In addition, a 2014 survey found that 62% did not realize that you cannot receive curative care at the same time as hospice care.

Go back to the basics, and take the time to ensure that your patients fully understand:

- [Which hospice services](#) are covered by Medicare and which are not. For example, Medicare does not cover round-the-clock in-home care or meal delivery.
- [How hospice care is paid for](#). Medicare, Medicaid, the Department of Veterans Affairs, and most private insurance companies cover hospice services.
 - Expenses like room and board at an inpatient facility are not always covered.
- That hospice is for anyone who has an advanced illness and meets specific criteria. A person does not need to be elderly, have cancer, or be in their last few days or weeks of life.
- That a do not resuscitate order is not required.
- That once they enter hospice, they can still choose to work with their current health care provider.
- That they are often able to receive hospice care where they live, including a nursing home or an assisted living facility, rather than at a dedicated hospice facility.
- That hospice care includes support and guidance for caregivers.

Helping your patients understand this information gives them the tools they need to make decisions about hospice and other end-of-life care options. And make sure your patient's family members and caregivers understand hospice, too.

Include Loved Ones in the Conversation

The beliefs and attitudes of your patient's caregivers and loved ones may have a profound effect on end-of-life care decisions and whether the patient's wishes are carried out.

As your patient's illness progresses, their loved ones will likely become more involved in their care, and the decision to enter hospice may eventually be up to them — which means they also need to understand the benefits of hospice.

Talking about the end of life is rarely easy, and even if a patient wants to go into hospice, they may avoid discussing their wishes with their family. Family members may be in denial about their loved one's prognosis. This denial — as well as complex family dynamics, conflicting views on hospice care, and the belief that hospice is expensive or involves taking someone away from their loved ones — can influence decisions about whether and when to enter hospice.

The influence of families and caregivers is particularly strong if they believe that their loved one could be saved by a miracle. In fact, one study found that caregivers who were making end-of-life decisions for a loved one and who believed in the possibility of a miracle sought more aggressive care and were less likely to use hospice services.

Involving all of the decision-makers early on can get everyone on the same page and further ensure that your [patient's end-of-life wishes will be met](#).

If your patient's loved ones approach you about the difficulty of discussing hospice, point them to <https://www.vnshealth.org/patient-family-support/guides/guide-to-advance-care-planning> VNS Health's Guide to Advance Care Planning, where they can learn about conversation starters and get tips.

Emphasize the Benefits of Hospice Care

It's not surprising that the term "hospice" is associated with death. However, that association can make people think that going into hospice means they are giving up, or even hastening death.

You don't need to sugarcoat your patient's condition, but you can talk about hospice in a more positive way.

Frame hospice as the right level of care at this point in their illness. Tell them it's a way to proactively choose emotional and medical support, autonomy, and comfort at the end of life. Talk about the fact that it doesn't mean they are giving up or that you are abandoning them.

Additionally, make sure your patients and their families understand that:

- Hospice does not shorten life expectancy. In fact, some studies have shown that people in hospice live longer than others with the same condition who do not go into hospice.[†]
- Although the patient can't get curative care for their terminal illness, they can still get care for conditions unrelated to the terminal illness, like high blood pressure, diabetes, and infections.
- Hospice has been shown to reduce the burden on caregivers.

Ask your patient about their hopes, wishes, and fears about end-of-life care. Answers to these questions will help you customize a plan that not only meets their needs but also helps them clearly see how hospice can benefit them.

Anticipate Cultural and Language Barriers

Cultural norms, religious beliefs, and race can be significant barriers to entering hospice care. In some cultures, talking about death is considered taboo. Nonwhite Americans utilize hospice services at significantly lower rates than white Americans, often because the former have experienced prejudice and they mistrust the health care system.

Although keeping these barriers in mind is critical when talking about hospice, avoiding generalizations is just as important. Everyone is different, and willingness to use hospice varies even among people who share the same beliefs and life experiences. Anticipate concerns but ultimately allow your patient and their caregivers to express hesitations before you make assumptions.

Language barriers can also prevent people from choosing hospice. Your exact words and body language can affect how your patient reacts to end-of-life care conversations. Even when interpreters are available, they often interpret only language — not your physical cues. So although your patient may technically get the information they need, they might not get the comfort and nuances that your words are meant to convey.

It's important to work with interpreters who have specialized training in communicating about topics like hospice. Hospice organizations, including VNS Health, are great resources for finding interpreters who can translate both your language and your empathy.

Keep the Conversation Going

The first time you bring up hospice, your patient and their loved ones might be hesitant; they may even give you an immediate “no.” Although it's important to respect their wishes, it's also important to reintroduce the topic as the patient's condition progresses and their needs change.

Whether it's your first time or your fifth time discussing end-of-life care with your patient, the conversation about hospice can be difficult for everyone involved. But it's an important one — and knowing how much you will be helping your patient have the best possible quality of life as they near the end of their life is worth it.

** [Medicare](#) covers advance care planning completely as long as it is part of a patient's yearly wellness visit. However, if it is provided as part of medical treatment, the Part B deductible and coinsurance apply.*

† Let your patients and their caregivers know that hospice care doesn't guarantee a longer life expectancy, so that you do not give them false hope.

VNS Health works with providers to ensure that patients and their families are getting everything they can from hospice care. <https://www.vnshealth.org/contact-us> to learn more about how VNS Health can support you as you talk to your patients and their loved ones about hospice.

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