

END OF LIFE PLANNING

The sooner a patient receives hospice care, the sooner the benefits of hospice care begin: more resources, pain and symptom management, specialized medical and nursing attention, emotional support for the patient and the family, assistance in planning and decision-making, and so on. Yet many patients are referred for hospice care later in their illness, there is little time to benefit fully. More patients may be able to receive hospice care earlier, as physicians become more comfortable discussing hospice in a way that patients can understand and accept.

The following is a six-step approach to discussing hospice care with patients and families:

- Establish an Appropriate Setting
- Learn What the Patient Knows
- Determine What the Patient Expects
- Discuss Hospice Care
- Respond to Emotions
- Establish a Plan

Establish an Appropriate Setting

- Talk in person. Choose a private, comfortable setting. Allot adequate time, and avoid interruptions. Ask if the patient would like anyone else to be present. If so, be willing to postpone the discussion.
- Some ways to begin are: “I’d like to talk to you about where we’re going with your care.” or “I’d like to review where we are and make plans for the future. Would you like your spouse/family to be here with you?”

Learn What the Patient Knows

- Ask an open-ended question, such as: “What do you understand about your illness?” or “How would you describe your medical situation?”
- If the patient does not share your understanding, determine whether he or she wants to hear the truth. People handle information differently. Sometimes they decline information and may designate someone else to communicate on their behalf. Possible questions to ask: “If this condition turns out to be something serious, do you want to know?” or “Would you like me to tell you the full details of your condition? If not, is there someone else you would like me to talk to?”
- You may find out that this is not the time to discuss hospice care.
- When you share an understanding with the patient about his/her health status, continue your discussion about hospice care.

Determine What the Patient Expects

- Ask patients to consider the future: “What do you see for yourself? What are you hoping for?”
- Most will say they want to be comfortable, stay at home, and not become a burden. Clarify what is likely or unlikely to happen. Ask follow-up questions to clarify what you expect and what the patient envisions. Be certain you share the same understanding of the overall goals of care.

Discuss Hospice Care

- Structure the conversation by using your insights into the patient’s values and goals. Introduce hospice care as a way of helping patients achieve their goals: “You’ve told me that you want to be as independent and comfortable as possible. You’ve also said you’d like to spend as much time as possible with your family in your own home. Hospice care is the best way I know of to help you achieve those goals.”
- Give information in small pieces. Use simple language. Pause frequently to assess reactions, ask for questions, or elicit concerns.
- Explain that hospice referral doesn’t mean that you and the medical team will abandon the patient, or stop striving for the patient to live “as well as possible, for as long as possible.”
- Offer to ask someone from the hospice program to come by simply to explain the details and answer questions. Call JourneyCare at 224-770-2489 to request that a hospice representative talk with your patient or the patient’s family.

Respond to Emotions

- Though outbursts of strong emotion, which are common, make many physicians uncomfortable, give the patient and family time to react. Listen quietly. Respond sympathetically. The best initial response may be silence and a box of tissues. Acknowledge that this is difficult for the patient: “I imagine this is difficult news...” “Tell me more about how you are feeling about what I just said.” “What worries you the most?” “Is there anyone you would like me to call?”
- Remember that once the emotion is “spent,” most people will be able to move on. Patients will appreciate that you are there for support.

Establish a Plan

- Discuss the next steps. Schedule your next meeting time. If the patient meets with the hospice team, meet with the patient (and family, if preferred) afterwards for further discussion. Once hospice care is agreed upon, let the patient know the name and phone number of the hospice agency you will refer them to, and that they will be contacted shortly. Let the hospice agency know about the discussions that preceded the referral, particularly if there was any family conflict involved.