

Difficult Conversations



AN END-OF-LIFE DISCUSSION GUIDE
FOR MEDICAL PROFESSIONALS

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Introduction

When a patient has a limited life expectancy, it can be difficult to initiate a conversation about end-of-life options. Medical professionals may worry that they will lose control of their patients' care by discontinuing curative treatment. This, they fear, may leave patients and their families feeling abandoned. Some clinicians view referral to hospice or comfort care as "giving up."

Although curative treatments may no longer be an option, there is always something more you can do for your patients. A hospice referral is an opportunity for them to receive comprehensive symptom management and continuing support.

We hope this booklet will provide a guideline for end-of-life care discussions with your patients. Although each patient will require an individual approach, it can be helpful to know how to begin.

"There's a common misconception that hospice care is giving up. Nothing could be further from the truth. Hospice provides high quality medical care...that maximizes quality of life and makes the wishes of the patient a priority."

— J. Donald Schumacher, PsyD, former president and CEO,
National Hospice and Palliative Care Organization

The Importance of the Conversation

Initiating the hospice conversation is the first step in helping a patient have a comfortable transition from curative to comfort care. As the patient's physician and a trusted professional, you can play an integral role in helping your patient develop a plan for end-of-life care. Patients are less likely to make the hospice decision without physician referral. Most people wait for their doctors to initiate these challenging discussions.

Initiate the conversation as soon as you suspect the illness is terminal. Though patients enrolled in the last weeks of life do benefit from hospice care, they cannot fully benefit from many of hospice's services. Hospice can help your patient by:

- Attending to the patient's physical, emotional, and social needs, and providing support and respite for caregivers
- Delivering care, medications, and medical supplies to wherever the patient lives, at no cost to the patient under Medicare/Medicaid and most insurance plans
- Providing assistance in making end-of-life decisions and allowing the patient to have a dignified death
- Offering bereavement support for families

"A large, diverse, and consistent body of evidence demonstrates that early discussions of serious illness care goals are associated with beneficial outcomes for patients, without harmful adverse effects."

— Rachelle E. Bernacki, MD, MS, and Susan D. Block, MD,
"Communication about Serious Illness Care Goals," *JAMA Internal Medicine*

When to Start the Conversation

Patients are eligible for hospice care when they have six months or less to live. However, clinicians agree that prognosticating life expectancy can be difficult. There may be many different factors to take into account. If any of the following apply to a patient, it may be time to discuss his or her preferences for end-of-life care:

- You would not be surprised if the patient died within a year
- The patient has a terminal illness such as end-stage cancer, ALS, Parkinson's Disease, dementia, COPD, congestive heart failure, renal disease, etc.
- Symptoms of the disease are becoming difficult to manage, or there is a steady or significant decline in the patient's condition, including:
 - Difficult-to-control pain
 - Dyspnea and/or dysphagia
 - Oxygen dependency
 - Diminished functional status
 - Dramatic weight loss
 - Decline in cognitive function
 - Recurrent infections
 - Multiple hospitalizations
- When the patient requests no further treatment, is discouraged by current treatment, or asks about hospice

The way you initiate an end-of-life care conversation depends on the patient's circumstances, your relationship with the individual, and what you feel is the best way to approach the topic. Consider using the following chart to help guide the hospice discussion.

Discussing End-of-Life Care with Your Patients


	SUGGESTIONS	WHAT YOU CAN DO OR SAY
Step 1: Set the Stage	<ul style="list-style-type: none"> • Initiate the conversation. Choose your words carefully to set the tone for the meeting. 	<i>"I'd like to talk about where we are with your care and make plans for the future."</i>
	<ul style="list-style-type: none"> • Include friends/family for emotional support. 	<i>"Would you like your wife to be here with you?"</i>
	<ul style="list-style-type: none"> • Allot adequate time. Rushing the conversation can leave patients feeling unsupported. 	Ask staff to hold calls and avoid interruptions. If you do not have time to review everything with the patient in one meeting, ask to schedule another appointment.
	<ul style="list-style-type: none"> • Allow for privacy and minimize distractions. 	Close the door or pull the curtain around the bed. Let the patient dress after an examination before starting the conversation. Silence all electronics, including phones and pagers.
	<ul style="list-style-type: none"> • Be aware of your body language. 	Sit at eye level beside the patient and make eye contact. Maintain a calm posture, avoiding nervous movements.
	<ul style="list-style-type: none"> • Be sensitive to cultural needs. Cultural differences may affect the way patients process information about an illness. 	Adjust your approach as needed and have a translator present if there are language barriers.
Step 2: Get Information	<ul style="list-style-type: none"> • Ask the patient what he or she understands about his or her health status. 	<i>"Tell me what you've been told about your illness." "How are you feeling about where you are with your illness?"</i>
	<ul style="list-style-type: none"> • Get permission to divulge information. Most patients will want to know everything about their illness, but some may not. 	<i>"How much information do you want me to give you about your illness? Do you want all of the details?"</i>
	<ul style="list-style-type: none"> • Determine the patient's goals of care. What is most important to the patient? If the patient mentions being tired of treatments or wanting comfort care, it may be a good time to introduce hospice. 	<i>"What do you hope to achieve with the current treatment, and what do you see for yourself in the future?"</i> You might also reflect on a recent setback or hospitalization and how it was difficult for the patient.
	<ul style="list-style-type: none"> • Be prepared for opposition. The patient may come to a different conclusion about the use of hospice care. 	If there is outright denial, don't press the issue. <i>"That's fine if you don't want to talk about this right now. Maybe we can discuss it later if your situation changes?"</i>
Step 3: Give Information	<ul style="list-style-type: none"> • Lead with a "warning statement" to give the patient a few moments to prepare for the news you are about to share. 	<i>"I'm so sorry to tell you..." "I wish that I had better news for you, but unfortunately..."</i>
	<ul style="list-style-type: none"> • Always be honest about prognosis. Resist softening the blow by encouraging false hope in a cure if there is little chance of recovery. 	Talk openly to the patient about what will happen. Some fears can be assuaged with straightforward information.
	<ul style="list-style-type: none"> • Speak slowly, clearly, and with expression. Pause often to ask questions; avoid doing all the talking. 	<i>"Do you have any questions?" "Is there anything you need me to explain further?"</i>
	<ul style="list-style-type: none"> • Give information in small pieces using simple language to be sure the patient fully understands what you are saying. 	Mirror the patient's language and avoid medical jargon. Ask the patient to explain the information to you in his or her own words before moving on.
Step 4: Provide Support	<ul style="list-style-type: none"> • Allow the patient to think, speak, and display emotion. The patient needs time to process thoughts and feelings. 	It's okay to have some silent moments during the discussion. Resist the urge to fill silences with more information.
	<ul style="list-style-type: none"> • Identify the patient's emotions and their causes. If you're not sure what the patient is feeling or why, ask open-ended questions. 	Asking <i>"How do you feel about the test results?"</i> is better than <i>"Are you disappointed with the test results?"</i>
	<ul style="list-style-type: none"> • Be supportive and empathetic to the patient's feelings or emotional outbursts. 	<i>"The results of the tests are very worrisome." "I can see why you would be so upset."</i>
	<ul style="list-style-type: none"> • Help the patient and family redirect hope for recovery into hope for a peaceful and comfortable end-of-life journey. 	<i>"There is still hope with comfort-only care. We can hope for better pain control and to maximize your quality of life from day to day."</i>
Step 5: Make a Plan	<ul style="list-style-type: none"> • Establish a care plan together, discussing the steps involved. Explain (or ask a hospice representative to explain) how hospice can help and how hospice services will be integrated. 	Clarify everyone's roles in the care plan. Reassure the patient that you will either be there every step of the way, or will be available if the patient needs to reach you.
	<ul style="list-style-type: none"> • Review what was discussed at the end of the conversation. 	Ask the patient if there are any other questions and schedule another meeting if you need more time to review.

At hospice, we value quality of life and share your goal of ensuring that each patient feels supported during his or her final days. For more information, or to ask a hospice representative to explain the details of hospice care to any patient, please contact us.

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