



PATHWAYS

Home Health, Hospice & Private Duty
Hospice Foundation

Hospice Care Guide

Questions & Answers

We're Here to Help



We know that when it is time to think about hospice care, you need your questions answered.

Most of us have little first-hand knowledge of hospice, and need facts to make the best possible health care decisions. Here we'll tell you about hospice care, and answer some of the common questions that people ask.

We welcome your call if you have more questions or would like to schedule an informational visit.

Call Pathways toll-free at 1.888.755.7855.

What is Hospice?



In the United States, hospice is a kind of care, not a place. Hospice is provided wherever you live. It is specialized care for people whose doctors believe they probably have six months or less to live.

People nearing the end of life often have many changes happening in a short period of time. There may be changes in medications, sleep habits, fatigue, diet, and family roles, to name just a few. It is the job of hospice to address each of these changes as they occur, to make the quality of life the best it can be.

Who pays for hospice?

Hospice is a benefit covered under Medicare, Medi-Cal, senior HMOs, regular HMOs and private insurance. Hospice pays for all medications, medical equipment and supplies that are related to the life-ending disease.

Is hospice care just for people with cancer?

No. Most patients on hospice do not have cancer. They may have emphysema, Alzheimer's, heart failure, kidney disease, Parkinson's, or any of many other diseases. Some people do not have a certain disease, but seem to be declining from old age.

How can I manage to care for my loved one at home?

Hospice nurses and other team members provide care during their visits, and they will teach you what you need to know to provide care at home.

Who comes to visit us?

Hospice care is provided by a team. Each patient has a nurse case manager. You can decide if you would also like a hospice aide to give personal care, a spiritual care counselor to talk to, a social worker to assist with arranging practical matters, or a volunteer to run errands or keep the patient company.



Can we visit our own doctor?

Yes. Your primary care doctor remains your doctor under hospice care. Your doctor gives us direction about your care.



Will someone come to stay with us?

No. Hospice does not provide shift care or 24-hour care. Team members make visits. But a nurse is available by telephone 24-hours a day and can come at any time if a visit is necessary.

Do I have to give up my medications?

No. Hospice will pay for your medications that are related to the terminal diagnosis. If there are medications that hospice does not cover, you can continue to get them and take them as you always have.

How will hospice manage pain if it occurs?

Hospice usually treats pain aggressively. We know that pain interferes with eating, sleeping, visiting and general quality of life. Uncontrolled pain can also shorten life.

The patient and family are always in control of their care and can decide how they want to treat pain.

Will my loved one be asleep all the time?

Not usually. Some diseases cause the patient to be less alert. If pain is severe, pain medicine may make a patient sleepier than usual for two or three days, then they will be as alert as the disease lets them be.

Does hospice do anything that will make my life shorter or longer?

No. Hospice tries to improve life in the final months or weeks, but does not try to shorten or lengthen life. Research shows that with the extra care from hospice people who go on hospice usually live longer than those who do not.

What about help with practical things like grocery shopping?

You can have a volunteer if you like. Volunteers can help you with practical matters such as shopping, or they can stay with your loved one while you go out.



What if caring for my loved one at home becomes too much for me to do?

If you feel you cannot continue caring for the patient at home, the hospice social worker can assist you to find a skilled nursing facility or residential care facility.

Can we go to the hospital?

Yes. You can always go to the hospital. Hospice asks that you call them first. They may be able to manage your crisis at home. If not, they can arrange transportation to the hospital. There are times that the hospice may ask you to go to the hospital for a short stay if there is a problem that can be managed better there.



My loved one lives in a nursing home. What can hospice do that they can't?

Nursing homes are experts in long-term care. Hospice nurses are experts in symptom management and end-of-life care. Hospice nurses are best equipped to deal quickly with health problems that arise. Other benefits of hospice include more frequent personal care, volunteer visitors, paid medications and supplies, and bereavement follow-up for family members.

When should we think about getting hospice help?

You can let your doctor know that you would like hospice care if it becomes appropriate. You are entitled to at least six months of care, but some doctors hesitate to talk about hospice for fear you will think they are “giving up.” Hospice is not giving up. Just like you, we hope you do well. Hospice is a way to be sure of the best care, no matter how things turn out.

Is hospice linked to a religion?

No. Hospice care is only related to health insurance. Because of the special nature of hospice care, we do make spiritual care counselors available to patients and families. They can also help to link you to someone in your own faith community.

Who decides whether we get hospice?

You do. Your doctor authorizes care, but you decide if you want this care or not. Sometimes the doctor calls hospice and asks us to contact you about hospice. Some families call hospice and have us contact the doctor to ask for authorization. Pathways will send someone, free of charge, to make an information visit if you need this.

Who makes our health care decisions when we are on hospice?

You and your doctor are always in control of your care. Hospice will make suggestions about your care, but you will always be in control.

What happens if my loved one is still alive at the end of six months?

Hospice must periodically recertify that the patient has a prognosis of six months or less. If at each of these dates it appears that the patient has six months or

less to live, then the patient can stay on hospice. If the course of the disease is slow, some people may be on longer than six months.

Can we stop hospice care?

Yes. Any patient can go off hospice at any time. You can also come back on hospice if circumstances change.

What if the patient's health improves?

Sometimes with the extra care from hospice a patient's health improves. They may start eating more and be more active. If they improve to the point that it looks like they will live more than six months, we will discontinue hospice care. The patient can return to hospice in the future when needed.

What does hospice do for us after my loved one dies?

A large part of hospice care is bereavement support for families and friends. Pathways provides phone calls, newsletters, counseling, support groups, and remembrance events for families after a death.

What Your Neighbors Say

"I thought maybe my mom would think we had given up. But it wasn't like that. She received wonderful care from friendly, kind, positive people, and she made her own decisions as long as she could."

—Son of Pathways Hospice Patient

"The Pathways Hospice team taught us and gave us advice, encouragement and reassurance. I know the end of his life was so much better than it might have been if we hadn't called Pathways."

—Wife of Pathways Hospice Patient

