The Truth About Hospice Care

Enrolling in hospice care isn't a death sentence. It's a unique opportunity to maximize quality of life when life expectancy appears to be limited. A palliative care expert explains the truth about hospice and how patients and families can make the most of this health service.

When you hear the word hospice, you may think of losing hope, dying and impending grief. But what you should think about is incredible support that maximizes quality of life and compassion for a loved one.

David Wu, M.D., an internal medicine and palliative care expert at Johns Hopkins Medicine, says, "Hospice care enables terminally ill patients to make the most of each day, focusing on comfort and quality of life when they should have it the most."

Understanding the Benefits of Hospice Care

Hospice care involves a unique team of doctors, nurses, chaplains, health aides, volunteers, social workers and administrative staff. The hospice team works together to manage symptoms (e.g., pain, nausea, anxiety and shortness of breath) and address any infections or other complications that may arise. The team also provides emotional and spiritual support. Some hospice programs include complementary care through music, art and massage therapy. "By focusing on the whole person and their family, hospice offers a level of comprehensive health support that is unmatched by any other medical care team," says Dr. Wu.

When it comes to hospice care, compassion, empathy and presence are paramount. "The hospice team walks with patients and families through their journey, helping them make the most of each day," notes Dr. Wu. "There's good evidence to support that this approach to care decreases symptoms, improves quality of care and improves family bereavement outcomes."

Dr. Wu dispels five common myths about hospice and offers his recommendations on the best time to consider it as an option for care.

Dispelling Common Myths About Hospice

Myth #1: Hospice refers to a specific place or facility.

> **Fact:** Hospice does not refer to a specific place. Rather, it refers to a team-based approach to care that is focused on comfort and quality of life. Hospice care can take place in the home, in an inpatient unit, in an assisted living facility or in a nursing home—wherever the patient wants or needs to be based on their individual circumstances.

Myth #2: Once you begin hospice, you give up your primary care or regular care doctor.

Fact: Patients and their families have the freedom to choose who will quarterback the hospice care plan. Patients have the right to keep their primary outpatient doctor as the main person in charge of coordinating care. For example, a patient with cancer might choose to have his or her primary oncologist continue to manage medical care.

Myth #3: Hospice care requires stopping all your medications.

Fact: Your hospice team will coordinate with you and your regular health providers to review all medications. The team will recommend which medications make sense to keep taking to maintain quality of life and comfort. For example, patients often benefit from continuing to take medications for blood pressure or diabetes.

Myth #4: Hospice is just for terminally ill cancer patients.

Fact: While hospice does help cancer patients, it can also provide significant benefits to patients with dementia, chronic obstructive pulmonary disease (COPD), congestive heart failure and other chronic conditions.

Myth #5: Once you sign up for hospice, you can't stop it.

Fact: You can sign out of hospice at any time and return to your past approach to medical care. Conversely, hospice can continue beyond six months if the patient is still showing signs of decline at that point.

Choosing the Best Time for Hospice

Unfortunately, most people don't take advantage of hospice care until the very end. "The median length of time for hospice care is only 23 days," explains Dr. Wu. "If more patients were enrolling in this underutilized service earlier, patients and their families could be benefiting from months of support and quality-of-life assistance."

So when should patients and families consider hospice care? Hospice should be considered when a patient has a life-limiting illness with a reasonable life expectancy of six months or less (in a doctor's opinion). Hospice may be appropriate if the illness is leading to a progressive decline and the patient and family are primarily focused on maximizing quality of life and comfort.

"If you're getting to the point of cycling in and out of the hospital without any real benefit, hospice may improve your quality of life significantly," says Dr. Wu. "At that point, patients and families should come together with their medical teams to discuss what is most important to them and how they want to spend the precious time they have left."

Getting Started with a Hospice Program

Your primary care doctor or social worker can provide some initial information about hospice care. In addition, the hospice administrative staff are more than happy to talk with patients and families about hospice care options and coordination.

The following steps are involved in starting hospice care:

1. The patient or physician consults with hospice administrative staff.
2. The hospice staff reviews the case to determine if it's an appropriate hospice scenario.
3. If hospice is applicable, an admission nurse is sent to meet with the patient and family. During this time, the patient is enrolled in the program. The patient and family are also educated about program details.
4. During all steps, hospice will take the lead in the coordination of care and make the process as smooth and seamless as possible for the patient and family.

What if you're curious about hospice but not ready to commit? "You can request a hospice information visit," explains Dr. Wu. "During the visit, a hospice liaison will discuss the hospice program with the patient and family. But there's no obligation to join hospice at that time."