

Script – Print – Understanding hospice

When it was announced in February 2023 that former President Jimmy Carter was going to receive hospice care at home for the remainder of his life, it was assumed by many that he was nearing the end of life. But now, one year later, the oldest-living former U.S. president is still living under hospice care and the goal remains the same – to make Mr. Carter as comfortable as possible with the time he has left.

While the average length of stay in hospice is 90 days, there are many people who die within a few days or some who live well past three months.

“A lot of people come on hospice care right at the end. And people will think, oh, you're going to die within a couple of days if you go on hospice care, and while that's true, unfortunately, those patients didn't get to benefit from all that hospice has to offer,” says Dr. Sarah Whelan, medical director for OSF Hospice and Outpatient Palliative Care in Rockford, Illinois. “But you can live quite a while on hospice care. Some patients will live past that six-month mark, as we've seen with Jimmy Carter, and that's, I think, a good thing. They're benefiting from the services we have to offer and having that quality time that they want at home and hopefully their symptoms managed so they can enjoy that time at home.”

Hospice is covered by private insurance, Medicare and Medicaid. For people who continue to live past the six-month mark, a hospice medical director or hospice doctor will need to recertify them for insurance to continue covering the cost of care. Dr. Whelan says she's cared for people for as many as two years in hospice.

“We just have to make sure they are continuing to want that non-aggressive symptom management approach and not returning to the hospital and that we see evidence of disease progression and more decline in their function and physical abilities,” she says.

Hospice started in England in 1967 by a physician, Dame Cecily Saunders, who worked on reducing the pain that cancer patients experienced at the end of life. In the U.S., hospice care became available in the mid-1970s, and thanks to lobbying and public education, hospice became a paid Medicare benefit in 1982.

According to the National Care Planning Council, there are about 3,200 hospice programs in the U.S. that serve 1 million Americans a year during their final days and months.

There are many myths about hospice, including:

- Hospice is a place: In fact, it's care that can be provided anywhere for the patient
- Hospice care is only provided by a nurse: There's an entire care team including a medical director, a physician, social workers, chaplains and a bereavement coordinator.
- Hospice is about giving up or hastening one's death. In fact, hospice is about having quality time at home.

“I really think hospice care is acceptance, more than giving up accepting that you're very sick and that the end may be near, but it's choosing to have some control over those last days of your life,” says Dr. Whelan. “And doing the things that you would like to do rather than struggling, along with aggressive medical care and things that might make you feel worse, but trying to do things that will help you feel better, spend those days how you would like.”

Finding the right hospice program for you or your loved one may seem daunting, but it doesn't have to be. Dr. Whelan says to ask for referrals, don't be afraid to ask questions about the services such as pain management, and make sure you are totally comfortable with your decision.

While hospice won't change the eventual outcome, the goal is to offer much-needed support to the patient and loved ones during those crucial last days or weeks.

"There's more than just medical things at the end of life," says Dr. Whelan. "There's a lot of spiritual and social and family things that people need to work through, and I think hospice does a really good job of helping people prepare for the end of their life and to help write that last chapter the way that they want to."

For more information on hospice, visit [OSF HealthCare](#).