

# Jimmy Carter's long stay in hospice dispels myths about end-of-life care

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Former President Jimmy Carter departs after the funeral service for former first lady Rosalynn Carter at Maranatha Baptist Church on November. 29, 2023, in Plains, Ga. The former first lady was 96. Pool Photo by Alex Brandon/UPI

NEW YORK, June 24 (UPI) -- Former President Jimmy Carter's being in hospice for 16 months makes him an "outlier," but it also highlights the

multifaceted nature of end-of-life care and dispels myths about that care, experts told UPI.

Carter, who is to turn 100 in October, entered hospice in February 2023 after deciding to discontinue aggressive treatment for metastatic melanoma.

Despite his decision, his surviving with the disease for more than 5 years, at his advanced age, should be considered a success, said Dr. Joan Teno, a former hospice provider and an expert in geriatric care.

"President Carter is an outlier in that only a small percentage of hospice patients survive more than 15 months," she told UPI in an email. "The fact that he has lived so long on hospice is testament to his excellent medical care at home and, if I had to guess, his will to live."

It also illustrates the core focus of hospice, which is typically geared toward people with an anticipated life expectancy of 6 months or less, for whom curing their underlying illness isn't an option, Teno added.



Most Americans don't engage in advance care planning and know little about care options at the end-of-life, according to Angela Novas of the Hospice Foundation of America. Photo courtesy of Angela Novas

The approach emphasizes symptom management -- most notably for pain -- and quality of life, according to the Hospice Foundation of America.

"While Hospice Foundation of America has worked for more than 40 years to educate people about the many benefits of hospice care, most Americans don't engage in advance care planning and know little about care options at the end of life," Angela Novas, the organization's senior medical officer, told UPI via email.



"I suspect that President Carter ... needs help in his everyday functions and uses a wheelchair," says former hospice provider Dr. Joan Teno. Photo courtesy of Dr. Joan Teno

"Because of that, there is a lot of confusion and misunderstanding about what hospice is, the care it provides, who qualifies and how to access care," she said.

### **Defying the odds**

More than 90% of patients who enter hospice care die within the first six months, and nearly 40% die within the first week, according to the National Institutes of Health.

Since entering hospice, though, Carter has celebrated his 99th birthday and grieved the death of his wife of 77 years, former first lady Rosalynn Carter, and was even able, with assistance, to attend her funeral.

"I suspect that President Carter is following the disease trajectory of [metastatic melanoma, which leads to] progressive fragility, where he needs help in his everyday functions and uses a wheelchair," said Teno, who has no direct knowledge of his health status.

Citing recent interviews with family members, the former president is likely spending most of his days sleeping, she said.

In general, hospice patients who are "not alert and sleeping more" are close to dying, said Teno, who is also an adjunct professor of health services, policy and practice at the Brown University School of Public Health.

"About two-thirds of [these patients] drift peacefully to sleep [as they die] -- I suspect that is what is happening," she added.

### **What end-of-life care entails**

The nuts and bolts of hospice vary by patient, but most providers adhere to Medicare guidelines and engage a multi-disciplinary team of health professionals trained to address the physical, psychosocial and spiritual needs of patients with terminal illnesses.

They also provide support to family members and other "intimate, unpaid" caregivers, according to the Hospice Foundation of America.

Teams typically include a hospice physician, nurse, medical social worker, home health aide and, if applicable, chaplain and/or spiritual adviser, the foundation says.

Services include medication for symptom control, including pain relief, medical equipment, such as a hospital bed, wheelchairs or walkers, and supplies, such as oxygen, bandages and catheters, as needed.

Many hospice patients receive physical and occupational therapy to maintain strength and mobility, as well as speech-language pathology services so that they can continue to communicate.

They also receive dietary counseling, which debunks "one of the most unhelpful myths" about hospice care that providers "limit nutrition and fluids or refuse to treat illnesses, such as an infection, that may occur while in hospice care to speed the dying process," the foundation's Novas said.

"This is simply not true," she said.

In some cases, "as part of the natural dying process, appetite diminishes significantly and patients frequently either refuse food and fluids or can no longer swallow safely without coughing and choking or aspirating food and fluids into their lungs, resulting in pneumonia," Novas said.

However, for as long as patients like Carter can tolerate food and fluids and find eating pleasurable, they are typically offered small portions of their favorite meals when they ask, she added.

"At end-of-life, hospice and family caregivers typically go with the flow of the day, which is dictated by how the hospice patient is doing," Novas said.

"It is likely that Mr. Carter has good days and bad days with waxing and waning of symptoms and abilities," she added.

Although she doesn't know specifics on the former president's daily regimen, on bad days, he may sleep for most of the day with little interaction with family or caregivers and a poor appetite, On good days, he may be alert, asking for food and be able to be out of bed and be engaged in life, Novas said,

"We have seen many photos of him during the time he has received hospice doing just that, and the hospice providing his care is highly focused on helping those opportunities happen," she said.

"Many hospice patients enjoy these good days or hours reminiscing with family and friends, reading, watching their favorite films or TV shows, or enjoying music," she added.

### **Hospice means home**

Being in hospice means that Carter, and others like him facing terminal illnesses, are able to stay at home, in comfort, surrounded by loved ones, according to the Hospice Foundation of America.

The service is provided primarily in the patient's home, whether that is a private residence, nursing home or community living arrangement, it says.

Hospice practitioners believe that being at home is best for people at end-of-life, both for reasons of comfort, as well as the reduced risk for hospital-acquired infections, which can add to suffering and reduce life expectancy, Novas said.

Still, hospice providers are available 24 hours a day, seven days a week to respond if the patient needs care.

Most hospice patients are eligible for Medicare, which covers all aspects of end-of-life care, and Medicaid offers similar coverage, according to the Hospice Foundation of America.

In addition, many commercial health insurance plans offer a hospice benefit, but the extent to which they cover care and services may vary.

"Certainly, Mr. Carter's choice to elect hospice care versus futile treatment has shone a spotlight on the value of hospice and palliative care and the important role it has in our healthcare system," Novas said.

"By outliving his initial prognosis and by receiving hospice care for over a year now, he has done much to dispel the myth that hospice is only for people who are bedbound and actively dying."