End-of-life decisions are always difficult, yet they're necessary choices most Americans will face for themselves or a loved one.

Americans spent $4.3 trillion on health care in 2021. It's estimated that 10% – $430 billion – of that was spent on end-of-life care and hospice costs. Nearly half of Medicare patients chose its hospice benefit, some for one or two days, some for six months or longer.

Studies find that hospice care can significantly lower the cost of end-of-life medical expenses, particularly if a patient spends more than 15 days in hospice.

Most end-of-life decisions are based not only on a patient's needs, but also on financial capability. Understanding hospice costs and other end-of-life options can help ease stress, and lead to decisions that benefit the patient and add to the quality of their last days.

## What Is End-of-Life Care?

End-of-life care is treatment is providing support and medical care for terminally ill patients to make their final days more comfortable. It can last for a few days, weeks, or even months. While someone may be terminally ill for years, Medicare, which is the benefit used by the majority of those in hospice care, determines "end of life" as someone who has a life expectancy of six months or less if the illness runs its normal course. Most insurers that provide hospice benefits follow Medicare's lead on that.

End-of-life care is not only medical, but also can involve physical comfort, support for mental, emotional, and spiritual needs, and practical care.

Hospice care focuses on comfort and quality of life, giving patients a compassionate end. Hospice is professionally administered, and it can take

place in hospitals, nursing homes, a special hospice or palliative unit or center, or the patient's own home. Studies consistently show 60%-70% of people say they prefer to die at home, and the majority of hospice care patients do.

With hospice care, symptoms are treated, but with no attempt to cure the illness. The aim is to make the patient as comfortable as possible. More than 70% of hospice providers are for-profit businesses that are paid by Medicare, Medicaid and other providers.

Palliative care is specialized treatment for people living with a serious illness and can be a form of hospice treatment, but isn't always.

The cost of hospice and palliative care is paid by Medicare, Medicaid, private insurance, charity or the individual, though more than 90% of hospice care in 2021 was to Medicare beneficiaries.

Medicare pays 100% of hospice costs, but when Medicare users enroll in the benefit, they agree to give up coverage for conventional treatment of their illness and its related conditions. More than 1.7 million Medicare beneficiaries elected the hospice benefit in 2021.

## Palliative Care

Palliative care is specialized medical care for someone with a life-threatening illness, and patients may receive medical care for their symptoms as well as treatment for their illness. The focus is on quality of life, as well as improved health. Palliative care starts with the diagnosis and continues until it's clear the patient won't survive.

## Hospice Care

Research shows that hospice care improves the mental health of patients and their families, increases survival time, decreases the strain on loved ones and does a better job keeping patients comfortable.

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Hospice care may be overseen by a doctor, but is usually provided by nurses, social workers, home health professionals and volunteers. They provide pain management, practical care and emotional support. The patient no longer is treated in an attempt to cure the illness, but rather to help relieve symptoms.

More than 90% of hospice beneficiaries receive care in their home. Some 1.7 million Medicare beneficiaries received hospice care from 5,358 providers in 2021, for a total $23.1 billion in costs. Of decedents who were Medicare beneficiaries in 2021, 47.3% were using the hospice benefit.

Medicare beneficiaries accounted for more than 90% of all hospice patient days in 2021, according to MedPAC, a government agency that analyzes the Medicare program.

There are also free-standing hospice centers, where a patient can stay and be cared for.

There are many options for hospice. The Centers for Medicare and Medicaid Services have a Hospice Compare displays information on the quality of care at each facility on its website. AARP also has a webpage on how to begin discussions on hospice and end-of-life care.

## Respite Care

Respite care is a short-term break for caregivers of terminally ill patients. It can be for a few hours, or several days. Medicare allows a patient to stay for up to five days in a Medicare-approved nursing home, hospital or hospice center in order to provide the caregiver a chance to recharge. There are also services that charge by the hour to care for the patient, allowing the caregiver to have some time off. Insurance doesn't always cover that service, so it's a good idea to check in with an insurer. The local AARP office or Agency on Aging also has caregiver resources that may include volunteer respite care help.

# Options for End-of-Life Care

There are many end-of-life care options. They can be driven by the patient's preference, the nature of the illness, insurance coverage, personal finances, religious considerations and more. Many studies show the majority of people say they want to die at home. In 2021, more people in America (31%) died at home than anywhere else for the first time since such statistics have been gathered, according to the Centers for Disease Control. Home, though, may not always be the best option, depending on circumstances.

Let's take a look at the options for end-of-life care.

## Hospitals

Hospitals offer around-the-clock medical care from doctors and nurses, a full range of treatment choices, modern medical equipment, teams of specialists, and immediate on-site tests and life-saving procedures.

Inpatient treatment adds cost to end-of-life care, but high-intensity hospital care is sometimes necessary, depending on the illness. To have hospital

hospice care covered by Medicare, a patient must have a symptom that can't be managed anywhere else.

Respiratory symptoms, influenza and COVID-19 are the most likely symptoms to land an older hospice patient in the hospital. About 76% of people 65 or older who died of pneumonia in 2021 died in an inpatient setting, as did 69% of those who died of influenza and COVID-19. Only 26% of those over 65 who died of other causes died in the hospital. Not all of these end-of-life patients were getting hospice care in the in-patient setting. In 2021, 396 of the 5,358 certified hospices in the U.S. were hospital-based. Since the Medicare hospice benefit doesn't cover certain hospital treatment, some patients choose to keep their traditional Medicare coverage to cover hospital costs.

## Nursing Homes

Nursing homes offer around-the-clock nursing care, and certified nursing homes offer skilled nursing care, which means that there are medical professionals on staff, though not always a doctor. A small number of nursing homes provide hospice care. In most cases, a nursing home resident receiving hospice care gets it through visits from a hospice agency. About 15% of hospice beneficiaries in 2021 were cared for in a nursing home, a decline from 2019, when it was 21%. The change was largely because of COVID-19 restrictions that limited visitors, including those from hospice providers, as well as chronic staffing issues at nursing homes. In 2021, there were 15,183 certified nursing homes in the U.S., providing care to 1.16 million residents, down from 15,523 in 2019, when there were 1.3 million residents, according to the Kaiser Family Foundation, which tracks healthcare statistics.

## A Patient's Home

Some 56% of people who received hospice care in 2021 got it at home, up from 49% in 2019. Patients were visited an average 3.8 times a week by a nurse, social worker or health care aide. Doctors don't visit, but will consult with the nurse or other hospice professional if needed. Medicare hospice provisions, as well as private insurance, have strict rules for whether a patient can be treated in a hospital, since in-patient treatment is so much more expensive. Many patients also prefer the comfort of home. Since most hospice care involves providing comfort, managing pain and practical care, a hospital setting isn't necessary.

## Free-Standing Hospice

These are healthcare residences that do nothing but provide hospice care. They are separate from a hospital, though some may be on a hospital campus. In 2021, 4,511 of the 5,358 hospices in the U.S. were free-standing. Many free-standing hospices also offer home-visit care, with their in-patient care for people who need more medical attention than home care can provide. They are almost all for-profit, and the only kind of hospice care that increased in 2021, with 7.7% growth.

## Board and Care Homes

Board and care homes are private, usually for-profit, residences that have a smaller number of residents than a nursing home (usually 20 or less). Care, meals and on-site staff are all provided, but not nurses or other medical care. A hospice provider would visit a patient at a board and care home, rather than be on the staff.

## Assisted Living Facilities

Residents of an assisted living facility are usually able to take care of themselves more independently than nursing home residents but need help

with some of their daily care. Residents have their own apartment or room, with shared dining area and other common space. Staff will help with medication, housekeeping, security, and more. Many have attached nursing homes, and if a resident can no longer care for themself, they can transition to the nursing home. Some provide hospice care, others would require visits from hospice care.

### Continuing Care Retirement Communities

Continuing care retirement communities, sometimes called life care communities, have a range of residential care options, from independent housing (houses or apartments), through assisted living and skilled nursing care, so patients can transition as they age or their health deteriorates.

## Who Pays for End-of-Life Care?

About 85% of end-of-life care costs are covered by government entities, with Medicare paying 85.4% of the bills. Managed care, private insurance and veterans benefits through the Department of Veterans Affairs cover most of what's left, with about 2.7% paid by the patient.

### Hospice

Medicare pays for all medically necessary hospital and doctor care under Parts A and B, regardless of cost or the condition of the patient. Medicare patients must specifically enroll in the hospice benefit in order to get it. Of the 3.4 million Americans who died in 2021, 2.75 million were Medicare beneficiaries at the time of death. Enrollment rises steadily with age. More than 59% of Medicare decedents in 2021 had the hospice benefit.

Medicare Hospice Benefit has paid for the care of eligible patients since 1982, and the growth of hospice in the U.S. is largely because of that benefit.

Eligibility for Medicare's Hospice Benefit:

- Patient must be 65 years or older.
- Diagnosed with a serious illness.
- Certification from a doctor that he or she has six months or less to live.
- Agrees to forgo life-saving or potentially curative treatment.
- Hospice provider must be Medicare-approved.

Medicare provides care for two 90-day periods in hospice, followed by an unlimited number of 60-day periods. At the start of each period of care, a doctor must recertify that the patient has six months or less to live.

Hospice provides four types of care:

- Routine home care, for which Medicare provides $207 a day for days 1-60.
- Routine home care, at $163 a day, for days 61 and after.
- Continuous home care, provided during periods of patient crisis, $1,492 a day.
- General inpatient care to treat symptoms that cannot be managed in another setting, $1,068 a day.
- Inpatient respite care for a short period to provide respite for primary caregiver, $473 a day.

The rates for Medicaid recipients are slightly higher.

Medicare's hospice coverage includes a broad range of services:

- Nursing care
- Medical social worker services
- Physician services
- Counseling (including dietary, pastoral and other types)
- Inpatient care
- Hospice aide and homemaker services
- Medical appliances and supplies (including drugs and biologicals)
- Physical and occupational therapies
- Speech-language pathology services
- Bereavement services for families

Hospice costs not covered by Medicare

- Room and board
- Emergency care such as ambulance fees or emergency room costs
- Treatment or prescription drugs attempting to cure illness

## Medicaid

Children with disabilities or adults who meet Medicaid's financial eligibility criteria are fully covered for end-of-life care under the program. Medicare beneficiaries who are dual-eligible for both programs (approximately 20% of all Medicare beneficiaries) can have Medicaid cover costs that Medicare doesn't cover, such as outpatient prescription drugs and long-term care.

Medicaid and Medicare's hospice eligibility requirements are almost identical: A patient must be certified to have six months or less to live and must receive services from a Medicare-certified hospice facility or agency. However, Medicaid policies can vary from state to state.

In addition to covering hospice services, Medicaid also pays at least 95% of room and board costs for hospice patients in a nursing home. Money is allocated to the hospice agency, which then pays the nursing home.

## Private Insurance

Private health insurance plans vary widely in terms of coverage. If the policy includes hospice, end-of-life care or palliative care, it will cover most of the costs.

Not all plans pay for hospice care, although most do since it is typically much less expensive than hospital treatment. Some policies that cover hospice care may have limits on hospice expenses.

## Other Payers

TRICARE is a health care program sponsored by the U.S. Department of Defense that provides health benefits for active military personnel and retirees, and their dependents. Hospice care is covered through this program.

CHAMPVA (Civilian Health and Medical Program of the Department of Veterans Affairs) is a health care program that insures eligible beneficiaries of certain deceased or disabled veterans. It covers most medically necessary care, including hospice.

Individuals without private health insurance, and who are not covered by a government policy, must pay for end-of-life care themselves. Some hospice care can be paid on a sliding scale, or through charitable or other donations.

# Costs of End-of-Life Care

Patients who needed hospital care in their final days paid much more than those in hospice.

A 2022 study found that care for terminal patients with non-sudden illnesses who spent 15 or more days in hospice cost 3.1% less than care for similar patients who didn't enroll in hospice. End-of-life care for patients, on average, cost $67,192, but dropped steadily after 15 days, down to $59,219 for those in hospice care for 266 days or longer.

The amount varies according to the illness and treatment needs. Someone with a neurodegenerative disease paid an average $61,004 in medical expenses, but someone with chronic kidney disease/end stage renal disease paid an average $82,781. The longer any patient is in hospice, the less their medical care costs, with the biggest decrease in the most expensive illnesses. Costs dropped 4% for the patient with the neurodegenerative illness, but were 27% less for the person with ckd/esr.

Another 2022 study, published in the Journal of American Medical Association, found hospice care improves the quality of end-of-life care, has lower healthcare costs, and, unlike many other aspects of the healthcare system, doesn't increase costs for the patient when it lowers costs for insurers.

Another study, by healthcare data analytics firm Trella Health, found that patients who did not elect the hospice Medicare benefit incurred as much as $27,455 in additional healthcare costs in their last months of life. Patients who enter hospice earlier in their illness saved an average of $14,000 during the last three months of life, compared to patients who were admitted for a mid-term stay.

“The research shows that hospice is undervalued for the amount of value it creates,” Trella CEO Ian Juliano said. “I don’t know of any other care setting that has remotely that type of return, based on the relatively small spend.

“It’s a very unique care setting, and it’s very obvious that it presents a wonderful return on investment for the payer, which in this case is usually the taxpayer.”

In 2021, the average hospice stay for decedents (Medicare beneficiaries who died that year), was 92.1 days, and the median was 17 days. Averages can skew high, because just a few people with long stays can affect the number; median means that half of the patients stayed longer and have for fewer days.

While the studies show that longer-term hospice care can save money, as well as provide a better quality of life for those with a life-ending illness in their final days, patients may not elect the benefit because they are concerned that they made need expensive treatment that won’t be covered. Industry experts say there’s also a psychological barrier – patients always hope they will get better and don’t want to “give up.” But families, in several surveys, said they appreciated the support and quality of life hospice provided their loved one.

Providers suggest patients with a life-threatening or terminal illness discuss hospice options with their doctor.