

Understanding Hospice

FACT SHEET

2025 Annual Lesson Series



As of 2024, former President Jimmy Carter is the oldest living former president in United States history. Carter, now 99, battled cancer and significant physical challenges over the years. When a life-limiting cancer returned, he “decided to spend his remaining time at home with his family and receive hospice care instead of additional medical intervention.” Carter’s decision to start hospice care brought national attention to this model of high quality, compassionate care.

What is Hospice?

Hospice focuses on comfort, not curing. It is a customized model of care that helps people with life-limiting illnesses live with dignity. Hospice focuses on maintaining quality of life for the person, rather than aggressively treating the disease or illness. Hospice is not giving up on life.

Hospice addresses the health and well-being of the whole person, including managing pain and the symptoms of disease, and providing emotional, spiritual, and social support for the person and their caregivers. The benefits of hospice include:

“You matter because you are you, and you matter to the end of your life. We will do all we can, not only to help you die peacefully, but also to live until you die.”

- Dame Cicely Saunders, founder of modern-day hospice.

- Developing a customized care plan.
- Managing pain and maximizing comfort.
- Maintaining independence for as long as possible.
- Upholding strong emotional bonds with family, friends, and caregivers.
- Supporting and providing instructions for caregivers.
- Assisting with daily tasks, such as bathing, dressing, and dining.
- Prescribing medications and medical equipment.
- Providing grief support and counseling.

There are four levels of hospice care: routine care, respite care, continuous care, and general inpatient care. Hospice care can be provided in various locations including residential homes, independent living communities, assisted living facilities, nursing homes, hospice houses, and hospitals.

The Hospice Team

Hospice utilizes a multi-disciplinary team of healthcare providers, other professionals, and volunteers to provide continuous or on-call care 24 hours a day, 7 days a week. The hospice team develops a customized care plan to meet the physical, social, emotional, and spiritual needs of the patient and family. Each person on the team has a unique role to play:

The Hospice Physician is responsible for easing the physical symptoms of the terminal illness and any conditions related to the illness.

A Registered Nurse provides nursing care and regular physical assessments, communicates with the attending hospice physician and/or hospice medical director, and makes sure an adequate supply of medications is on hand.

A Hospice Aide provides hands-on assistance with various needs, including personal care and daily activities.

A Chaplain, if desired, assists with the spiritual experience of a terminal illness. These services include regular pastoral care visits, being on-call in the event of a crisis, providing grief support, and assistance with funerals and memorial services.

The Hospice Social Worker helps identify community resources such as private care agencies, government resources, and counseling services. The social worker can also help with advanced health care directives.

Community Volunteers can provide the primary caregiver with a short break from their care responsibilities (this is called respite care).

Qualifying for Hospice Care and Cost of Care

People become eligible for hospice care when they have been diagnosed by a physician with a terminal illness having a prognosis of six months or less to live if the disease runs its normal course. Hospice candidates must agree to the terms of care based on the current hospice benefits. A signed medical order from a provider is required to perform an evaluation to determine eligibility.

Most hospice patients have their costs covered by Medicare through the Medicare Hospice Benefit. Medicaid, the Department of Veterans Affairs, most private insurance plans, and other managed care organizations may also cover hospice care. If insurance coverage is not available or does not cover all costs, services may be paid for out-of-pocket. Sometimes, hospice providers offer care at no cost or a reduced price to those without insurance coverage or who otherwise could not afford hospice services.

“Before hospice, I could not get my husband in the shower. Now, it is no longer a problem. Arranging respite care has also been a life saver. As the only caregiver for my husband, this gives me time to do things without constant worry. Hospice has made a big difference in our lives.”

- Nancy, caregiver for husband with dementia.

Finding a Hospice Provider

To find a hospice provider, it is recommended to first talk with a person’s primary care provider or call the state hospice organization. State hospice organization information can be found by calling 1-800-MEDICARE (1-800-633-4227). It is also helpful to ask for recommendations from families who have used hospice services before.

Medicare only covers hospice care if the hospice provider is approved by Medicare. Individuals receiving veterans benefits and those belonging to Medicare Advantage Plans, other managed care organizations, or private insurance plans are encouraged to contact their plan directly to locate an approved hospice provider.



Five Myths About Hospice

MYTH: Hospice is only for the last weeks or days of one's life.

Hospice can begin when a physician determines a person has approximately six months or less to live. Pain management and comfort care give a person an improved quality of life and more comfortable days.

MYTH: Hospice means you have given up.

Receiving hospice care does not mean that you have given up hope. The focus of care is to provide a person with a better quality of life, be more comfortable, and feel more like themselves. Sometimes, people will go on and off hospice if their health improves, if they no longer qualify for services, or if they choose to pursue treatments.

MYTH: Hospice care hastens death.

People sometimes associate medication used for pain control, such as morphine, with a person's death. Remember, the person on hospice is already entering the last stages of their life. In many instances, controlling pain and discomfort allows the person to live longer.

MYTH: Sedation is common and widely used.

Hospice providers do not intentionally sedate patients to deal with severe pain. People with chronic pain are started on low dosages of medication to see if it will alleviate their symptoms. Higher doses of pain medication are administered if pain persists.

MYTH: Hospice care is just for the dying patient.

Hospice also provides caregiving assistance and grief counseling for family members and caregivers. Most providers offer these bereavement services up to 13 months after the patient's death.

Talking about Hospice and End-of-Life Wishes

Ideally, discussing end-of-life choices should happen before a medical crisis or diagnosis. Anyone can be better prepared for the unexpected by having Advance Healthcare Directives in place. These directives allow you to choose someone you trust to speak for you if you cannot speak for yourself (durable power of attorney for healthcare) and/or communicate your end-of-life wishes in writing (living will). Without these directives, loved ones may have to assume what you would have wanted. This can create stress and even family disagreements.

Having a conversation about end-of-life decisions is not an easy topic, but it is important and necessary. When your loved ones know your wishes, it is likely that you will receive the type of care you want. Sometimes, getting the conversation started can be the hardest part. Here are some examples of how to start the conversation with your family:

- “Can we sit down to talk about _____?”
- “I was considering what happened to _____, and it got me thinking about what I would want in that situation.”
- “I want to be prepared for the future, and I want you to know my healthcare wishes.”
- “Will you help me think about my future healthcare?”
- “When _____ died, do you think their wishes and priorities were respected toward the end of their life?”

When you are thinking about your end-of-life care, ask yourself:

- What does a good day look like for me?
- Who supports me during challenging times?
- What matters most when thinking about my end-of-life experience?
- Are there any treatments I would not want to have near the end of my life?
- If my health condition changes, when would it be okay to shift from trying to cure an illness to trying to enjoy the end of life as much as possible?

Conclusion

Hospice gives a person the freedom to choose how they wish to spend their remaining days. The goal of hospice is to respect the person's wishes by providing comfort, dignity, and quality of life. It also helps family members by offering emotional and caregiving support during a challenging time. Having family conversations allows us to recognize the benefits of hospice, acknowledge our own wishes, and inform others of what is most important to us. As Dame Cicely Saunders said, "You matter because you are you, and you matter at the end of your life."

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Authors

Kathy Goul, *Family and Consumer Science Agent, K-State Research and Extension, Marais des Cygnes District*

Teresa Hatfield, *M.A., Family and Community Wellness Agent, K-State Research and Extension, Meadowlark District*

Erin Martinez, *Ph.D., Associate Professor and Extension Specialist, College of Health and Human Sciences*

Reviewers

Tony Erisman, *MS, Senior Hospice Consultant, Good Shepherd Hospice*

Jami DeGrave, *BSN RN, Regional Director of Hospice Operations, Sacred Heart Health, Faith Home Health & Hospice*

Naomi Meinertz, *Ph.D., Assistant Professor and State Specialist, University of Missouri*

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