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Local Service Category:	Hospice Services
Amount Available:	To be determined
Unit Cost	
Budget Requirements or Restrictions:	Maximum 10% of budget for Administrative Cost
DSHS Service Category Definition:	Provision of end-of-life care provided by licensed hospice care providers to people living with HIV (PLWH) in the terminal stages of an HIV-related illness, in a home or other residential setting, including a non-acute-care section of a hospital that has been designated and staffed to provide hospice care for terminal patients. Hospice services include, but are not limited to, the palliation and management of the terminal illness and conditions related to the terminal illness. Allowable Ryan White/State Services funded services are: Board Mental health counseling, to include bereavement counseling
Local Service Category	 Physician services Palliative therapeutics Ryan White/State Service funds may not be used for funeral, burial, cremation, or related expenses. Funds may not be used for nutritional services, durable medical equipment and medical supplies or case management services. Hospice services encompass palliative care for terminally ill PLWH
Definition:	and support services for PLWH and their families. Services are provided by a licensed nurse and/or physical therapist. Additionally, unlicensed personnel may deliver services under the delegation of a licensed nurse or physical therapist, to a PLWH or a PLWH's family as part of a coordinated program. A physician must certify that a patient is terminal, defined under Medicaid hospice regulations as having a life expectancy of 6 months or less.
	Services must include but are not limited to medical and nursing care, palliative care, and psychosocial support for the patient, as well as a mechanism for bereavement referral for surviving family members. Counseling services provided in the context of hospice care must be consistent with the (Ryan White) definition of mental health counseling. Palliative therapies must be consistent with those covered under respective State Medicaid Program.
Target Population (age, gender, geographic, race, ethnicity, etc.):	People living with HIV and having a life expectancy of 6 months or less residing in the Houston HIV Service Delivery (HSDA).
Services to be Provided:	Services must include but are not limited to medical and nursing care,

	palliative care, psychosocial support and spiritual guidance for the patient, as well as a mechanism for bereavement referral for surviving family members. Counseling services provided in the context of hospice care must be consistent with the (Ryan White) definition of mental health counseling. Palliative therapies must be consistent with those covered under respective State Medicaid Program.
	Allowable Ryan White/State Services funded services are: • Room
	• Board
	Nursing care
	Mental health counseling, to include bereavement counselingPhysician services
	Palliative therapeutics
	Services NOT allowed under this category:
	 HIV medications under hospice care unless paid for by the
	PLWH.
	• Medical care for acute conditions or acute exacerbations of
	chronic conditions other than HIV for potentially Medicaid
	eligible residents.
	• Funeral, burial, cremation, or related expenses.
	• Nutritional services,
	• Durable medical equipment and medical supplies.
	• Case management services.
	• Although Texas Medicaid can pay for bereavement counseling for family members for up to a year after the patient's death and can
	be offered in a skilled nursing facility or nursing home, Ryan
	White funding CANNOT pay for these services per legislation.
Service Unit Definition(s):	A unit of service is defined as one (1) twenty-four (24) hour day of
	hospice services that includes a full range of physical and
	psychological support to HIV patients in the final stages of AIDS.
Financial Eligibility:	Income at or below 300% Federal Poverty Guidelines.
Eligibility for Services:	Individuals with an AIDS diagnosis and certified by his or her
	physician that the individual's prognosis is for a life expectancy of six
	(6) months or less if the terminal illness runs its normal course
Agency Requirements:	Agency/provider is a licensed hospital/facility and maintains a valid
	State license with a residential AIDS Hospice designation or is certified
	as a Special Care Facility with Hospice designation.
	Provider must inform Administrative Agency regarding issue of long-
	term care facilities denying admission for people living with HIV based
	on inability to provide appropriate level of skilled nursing care.
	Services must be provided by a medically directed interdisciplinary
	team, qualified in treating individual requiring hospice services.
	team, quantice in accuring marriadul requiring hospice services.

	Staff will refer Medicaid/Medicare eligible PLWH to a Hospice Provider for medical, support, and palliative care. Staff will document
	an attempt has been made to place Medicaid/Medicare eligible PLWH
	in another facility prior to admission.
Staff Requirements:	All Hospice care staff who provide direct-care services and who require
	licensure or certification, must be properly licensed or certified by the
	State of Texas.
Special Requirements:	These services must be:
	a) Available 24 hours a day, seven days a week, during the last stages
	of illness, during death, and during bereavement;
	b) Provided by a medically directed interdisciplinary team;
	c) Provided in nursing home, residential unit, or inpatient unit according to need. These services do not include inpatient care normally provided in a licensed hospital to a terminally ill person who has not elected to be a hospice PLWH.
	d) Residents seeking care for hospice at Agency must first seek care from other facilities and denial must be documented in the resident's chart.
	Must comply with the Houston HSDA Hospice Standards of Care . The agency must comply with the DSHS Hospice Standards of
	Care . The agency must have policies and procedures in place that
	comply with the standards <i>prior</i> to delivery of the service.

FY 2028 RWPC "How to Best Meet the Need" Decision Process

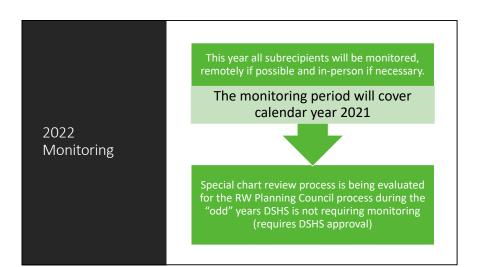
Step in Process: C	ouncil		Date: 06/12/2025
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Step in Process: St	eering Committee		Date: 06/05/2025
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Step in Process: Q Recommendations:	uality Improvement Committ Approved: Y: No:		Date: 05/13/2025 ed with changes list
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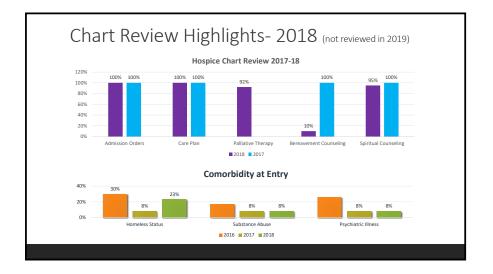
Modified Monitoring Process Effective March 13, 2020 TRG enacted emergency response procedures due to COVID-19 pandemic. All monitoring was deferred/suspended in 2020 per DSHS and HRSA guidance.

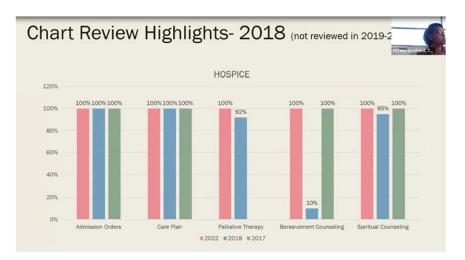
In 2020, DSHS launched a burden reduction plan to reduce administrative burden by 50% for AA's and Subrecipients.

- This model requires subrecipient monitoring every other year (even years only).
- Per DSHS guidance, TRG is not required to complete monitoring in odd years
- In 2020, subrecipients that didn't have the ability to complete a remote review, were exempted from the 2020 Standards of Care chart review monitoring due to the COVID-19 State of Emergency.









https://www.nia.nih.gov/health/end-life/providing-care-and-comfor...

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Providing Care and Comfort at the End of Life

On this page:

- What is end-of-life care?
- End of life: Providing physical comfort
- End of life: Managing mental and emotional needs
- Spiritual needs at the end of life
- Providing support for practical tasks

Not all end-of-life experiences are alike. Death can come suddenly, or a person may linger in a near-death state for days. For some older adults at the end of life, the body weakens while the mind stays clear. Others remain physically strong while <u>cognitive function</u> declines. It's common to wonder what happens when someone is dying. You may want to know how to provide comfort, what to say, or what to do.

In this article, you will read about ways to help provide care and comfort to someone who is dying. Such care often involves a team: Always remember to check with the person's health care team to make sure these suggestions are appropriate for the situation.

What is end-of-life care?

End-of-life care is the term used to describe the support and medical care given during the time surrounding death. This type of care does not happen only in the moments before breathing ceases and the heart stops beating. Older people often live with one or more chronic illness and need significant care for days, weeks, and even months before death.

The end of life may look different depending on the person's preferences, needs, or choices. Some people may want to be at home when they die, while others may prefer to seek treatment in a hospital or facility until the very end. Many want to be surrounded by family and friends, but it's common for some to slip away while their loved ones aren't in the room. When possible, there are steps you can take to increase the likelihood of a peaceful death for your loved one, follow their end-of-life wishes, and treat them with respect while they are dying.

Generally speaking, people who are dying need care in four areas: <u>physical</u> <u>comfort, mental and</u>



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emotional needs, spiritual needs, and practical tasks. Of course, the family of the dying person needs support as well, with practical tasks and emotional distress.



End of life: Providing physical comfort

Discomfort during the dying process can come from a variety of sources. Depending on the cause of the discomfort, there are things you or a health care provider can do to help make the dying person more comfortable. For example, the person may be uncomfortable because of:

- Pain
- Breathing problems
- Skin irritation, including itching
- Digestive problems
- Temperature sensitivity
- Fatigue

Pain. Not everyone who is dying experiences pain. For those who do, experts believe that care should focus on relieving pain without worrying about possible long-term problems of drug dependence or abuse.

Struggling with severe pain can be draining and make the dying person understandably angry or short-tempered. This can make it even harder for families and other loved ones to communicate with the person in a meaningful way.

Caregivers and other family members can play significant roles in managing a dying person's pain. But knowing how much pain someone is in can be difficult. Watch for clues, such as trouble sleeping, showing increased agitation, or crying. Don't be afraid of giving as much pain medicine as is prescribed by the doctor.

Pain is easier to prevent than to relieve, and severe pain is hard to manage. Try to make sure that the level of pain does not get ahead of pain-relieving medicines. Tell the health care professionals if the pain is not controlled because medicines can be increased or changed. Palliative medical specialists are experienced in pain management for seriously ill patients; consider consulting with one if they're not already involved (see <u>What Are</u> <u>Palliative Care and Hospice Care?</u>).

What about morphine and other painkillers?

Morphine is an opiate, a strong drug used to treat serious pain. Sometimes, morphine is also given to ease the feeling of shortness of breath. Successfully reducing pain and addressing concerns about breathing can provide needed comfort to someone who is close to dying. Side effects may include

confusion, drowsiness, or hallucinations. Talk with the person's health care team if you have any questions about the side effects of morphine or other pain medications.

Breathing problems. Shortness of breath or the feeling that breathing is difficult is a common experience at the end of life. The doctor might call this dyspnea. To help ease breathing for your loved one, try raising the head of the bed, opening a window, using a humidifier, or using a fan to circulate air in the room. Sometimes, morphine or other pain medications can help relieve the sense of breathlessness.

There may be times when a dying person has an abnormal breathing pattern, known as Cheyne-Stokes breathing. The person's breathing may alternate between deep, heavy breaths and shallow or even no breaths. Some people very near death might have noisy breathing, sometimes called a death rattle. In most cases, this noisy breathing does not upset the dying person, though it may be alarming to family and friends. You may try turning the person to rest on one side or elevating their head. Prescription medicine may also help.

Skin irritation. Skin problems can be very uncomfortable for someone when they are dying. Keep the person's <u>skin</u> clean and moisturized. Gently apply alcohol-free lotion to relieve itching and dryness.

Dryness on parts of the face, such as the lips and eyes, can be a common cause of discomfort near death. These tips may help:

- Keep their lips moist with lip balm and their mouth clean with a soft, damp cloth.
- Gently dab an eye cream or gel around the eyes.
- Try placing a damp cloth over the person's closed eyes.
- If the inside of the mouth seems dry, giving ice chips (if the person is conscious) or wiping the inside of the person's mouth with a damp cloth, cotton ball, or specially treated swab might help.

Sitting or lying in one position can put constant pressure on sensitive skin, which can lead to painful bed sores (sometimes called pressure ulcers). When a bed sore first forms, the skin gets discolored or darker. Watch carefully for these discolored spots, especially on the heels, hips, lower back, and back of the head.

Turning the person in bed every few hours may help prevent bed sores and stiffness. Try putting a foam pad under the person's heel or elbow to raise it off the bed and reduce pressure. Ask a member of your health care team if a special mattress or chair cushion might also help.

Digestive problems. Nausea, vomiting, <u>constipation</u>, and loss of appetite are common issues at the end of life. Swallowing may also be a problem. The causes and treatments for these symptoms vary, so talk to a doctor or nurse about what you're seeing. Medicines can control nausea or vomiting or relieve constipation, all of which are common side effects of strong pain medications.

If the person loses their appetite, try gently offering favorite foods in small amounts. Serve frequent, smaller meals rather than three larger ones. Help with feeding if the person wants to eat but is too tired or weak.

But don't force a dying person to eat. Losing one's appetite is a common and normal part of dying. Going without food and/or water is generally not painful, and eating and drinking can add to a dying person's discomfort. A conscious decision to give up food can be part of a person's acceptance that death is near.

Temperature sensitivity. When a person is closer to death, their hands, arms, feet, or legs may be cool to the

touch. Some parts of the body may become darker or blueish. People who are dying may not be able to tell you that they are too hot or too cold, so watch for clues. For example, someone who is too warm might repeatedly try to remove a blanket. You can remove the blanket and place a cool cloth on the person's head.

Hunching their shoulders, pulling the covers up, and shivering can be signs the person is cold. Make sure there is no draft, raise the heat, and add another blanket. Avoid electric blankets because they can get too hot.

Fatigue. It is common for people nearing the end of life to feel tired and have little or no energy. Keep things simple. For example, a bedside commode can be used instead of walking to the bathroom. Providing a stool so the person can sit in the shower, or sponge baths in bed can also help.

Meena's story

At 80, Meena had been in a nursing home for two years following her **stroke**. Eventually, her health declined, and she was no longer able to communicate her wishes. Meena's physician, Dr. Torres, told her family she was dying. She said that medical tests, physical therapy, and treatments were no longer needed and should be stopped because they might be causing Meena discomfort. Also, so they would not interrupt her rest, Dr. Torres said the health care team would stop regularly checking vital signs, such as pulse and blood pressure. Then, Meena developed **pneumonia**. Her family asked about moving her to the hospital. Dr. Torres explained that Meena could get the same care in the nursing home and that a move could disturb and confuse her. The family agreed, and Meena died two days later in familiar surroundings with her loved one's present.

End of life: Managing mental and emotional needs

End-of-life care can also include helping the dying person manage mental and emotional distress. Someone who is alert near the end of life might understandably feel <u>depressed</u> or anxious. It is important to treat emotional pain and suffering. You might want to contact a counselor, possibly one familiar with end-of-life issues, to encourage conversations about feelings. Medicine may help if the depression or anxiety is severe.

The dying person may also have some specific fears and concerns. He or she may fear the unknown, or worry about those left behind. Some people are afraid of being alone at the very end. These feelings can be made worse by the reactions of family, friends, and even the medical team. For example, family and friends may not know how to help or what to say, so they stop visiting, or they may withdraw because they are already grieving. Doctors may feel helpless and avoid dying patients because they cannot help them further.

And some people may experience mental confusion and may have strange or unusual behavior, making it harder to connect with their loved ones. This can add to a dying person's sense of isolation.

Here are a few tips that may help manage mental and emotional needs:

- Provide physical contact. Try holding hands or a gentle massage.
- Set a comforting mood. Some people prefer quiet moments with less people. Use soft lighting in the room.
- Play music at a low volume. This can help with relaxation and lessen pain.
- Involve the dying person. If the person can still communicate, ask them what they need.

• **Be present**. Visit with the person. Talk or read to them, even if they can't talk back. If they can talk, listen attentively to what they have to say without worrying about what you will say next. Your presence can be the greatest gift you can give to a dying person.

Spiritual needs at the end of life

For people nearing the end of life, spiritual needs may be as important as their physical concerns. Spiritual needs may include finding meaning in one's life, ending disagreements with others, or making peace with life circumstances. The dying person might find comfort in resolving unsettled issues with friends or family. Visits from a social worker or a counselor may help.

Many people find solace in their faith. Others may struggle with their faith or spiritual beliefs. Praying, reading religious texts, or listening to religious music may help. The person can also talk with someone from their religious community, such as a minister, priest, rabbi, or imam.

Family and friends can talk to the dying person about the importance of their relationship. For example, adult children may share how their father has influenced the course of their lives. Grandchildren can let their grandfather know how much he has meant to them. Friends can share how they value years of support and companionship. Family and friends who can't be present in person can send a video or audio recording of what they would like to say, or a letter to be read out loud.

Sharing memories of good times is another way some people find peace near death. This can be comforting for everyone. Some doctors think that dying people can still hear even if they are not conscious. Always talk to, not about, the person who is dying. When you come into the room, identify yourself to the person. You may want to ask someone to write down some of the things said at this time — both by and to the person who is dying. In time, these words might serve as a source of comfort to family and friends.

There may come a time when a <u>dying person who has been confused</u> suddenly seems to be thinking clearly. Take advantage of these moments but understand that they are likely temporary and not necessarily a sign of getting better. Sometimes, a dying person may appear to see or talk to someone who is not there. Resist temptation to interrupt or correct them, or say they are imagining things. Give the dying person the space to experience their own reality. Sometimes dying people will report having dreams of meeting deceased relatives, friends, or religious figures. The dying person may have various reactions to such dreams, but often, they are quite comforting to them.

Should there always be someone in the room with a dying person?

Staying close to someone who is dying is often called keeping a vigil. It can be comforting for the caregiver or other family members to always be there, but it can also be tiring and stressful. Unless your cultural or religious traditions require it, do not feel that you must stay with the person all the time. If there are other family members or friends around, try taking turns sitting in the room.

Providing support for practical tasks

Many practical jobs need to be done at the end of life - both to relieve the person who is dying and to support

<u>the caregiver</u>. A person who is dying might be worried about who will take care of things when they are gone. A family member or friend can offer reassurance — "I'll make sure your African violets are watered," "Jessica has promised to take care of Bandit," "Dad, we want Mom to live with us from now on" — which may help provide a measure of peace. You also may remind the dying person that their personal affairs are in good hands.

Everyday tasks can also be a source of worry for someone who is dying and can overwhelm a caregiver. A family member or friend can provide the caregiver with a much-needed break by helping with small daily chores around the house such as picking up the mail, writing down phone messages, doing a load of laundry, feeding the family pet, or picking up medicine from the pharmacy.

Caregivers may also feel overwhelmed keeping close friends and family informed. A family member or friend can help set up an outgoing voicemail message, a blog, an email list, a private Facebook page, or even a phone tree to help reduce the number of calls the caregiver must make. Listed at the end of this article are some organizations that make setting up such resources easy and secure.

How can family and friends help primary caregivers?

Family and friends may wish to provide primary caregivers relief while they are focusing on the dying loved one. Keep in mind that the caregiver may not know exactly what is needed and may feel overwhelmed by responding to questions. If the caregiver is open to receiving help, here are some questions you might ask:

- How are you doing? Do you need someone to talk with?
- Would you like to go out for an hour or two? I could stay here while you are away.
- Who has offered to help you? Do you want me to work with them to coordinate our efforts?
- Can I help ... maybe walk the dog, answer the phone, go to the drug store or the grocery store, or watch the children (for example) ... for you?

Providing comfort and care for someone at the end of life can be physically and emotionally exhausting. If you are a primary caregiver, <u>ask for help when you need it</u> and accept help when it's offered. Don't hesitate to suggest a specific task to someone who offers to help. Friends and family are usually eager to do something for you and the person who is dying, but they may not know what to do.

In the end, consider that there may be no "perfect" death so just do the best you can for your loved one. The deep pain of losing someone close to you may be softened a little by knowing that, when you were needed, you did what you could.

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NHPCO Facts and Figures

2024 EDITION Published September 2024



For over two decades, the National Hospice and Palliative Care Organization (NHPCO) has published its annual NHPCO Facts and Figures report, providing an overview of hospice care delivery.

At time of this report's publication, NHPCO is in the process of forming a new, joint organization with the National Association for Home Care & Hospice, the National Alliance for Care at Home.



The National Alliance for Care at Home will bring the important work of Facts and Figures forward with an increased focus on data and research representing the broader care-at-home community.



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Section 1: Introduction

About this Report

NHPCO Facts and Figures provides an annual overview of hospice care delivery. This overview provides specific information on:

- Hospice patient characteristics
- I ocation and level of care
- Medicare hospice spending
- Hospice provider characteristics
- Quality of care

Currently, most hospice patients have their costs covered by Medicare through the Medicare Hospice Benefit.

Impact of COVID-19

This year, COVID-19 continued to impact patient care as COVID-19 waivers were still in place through May 2023. These waivers included increased telehealth services. Utilization of hospice has not returned to pre-pandemic rates but has increased since 2020 (see Section 3). Due to the impact of COVID-19 on data from 2020, 2020 data is not included in many of the charts this year.

and Medicaid Services (CMS) and reimbursed under the Medicare Hospice Benefit.

What is hospice care?

Considered the model for quality, compassionate care for people facing a life-limiting illness, hospice provides expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes. Support is provided to the patient's loved ones as well.

Hospice focuses on caring, not curing. In most cases, care is provided in the patient's private residence, but may also be provided in freestanding hospice facilities, hospitals, nursing homes, assisted living facilities, or other long-term care facilities. Hospice services are available to patients with any terminal illness. Hospice providers promote inclusivity in the community by ensuring all people regardless of race, ethnicity, color, religion, gender, disability, sexual orientation, age, disease, or other characteristics have access to high-quality, end-of-life care.

How is hospice care delivered?

Typically, a family member serves as the primary caregiver and, when appropriate, helps make decisions for the terminally-ill individual. Members of the hospice staff make regular visits to assess the patient and provide additional care or other services. Hospice staff are on-call 24 hours a day, seven days a week.

Introduction (continued)

The hospice team develops a care plan to meet each patient's individual needs for pain management and symptom control. This interdisciplinary team (IDT), as illustrated in Figure 1, usually consists of the patient's personal physician; hospice physician or medical director; nurses; hospice aides; social workers; bereavement counselors; spiritual care providers; and trained volunteers. In addition to the IDT, the hospice will support the physical, psychosocial, and spiritual needs of the beneficiary.

What services are provided?

The hospice interdisciplinary team:

- Manages the patient's pain and other symptoms
- Assists the patient and loved ones with the emotional, psychosocial, and spiritual aspects of dying
- Provides medications and medical equipment
- Instructs the informal caregivers on how to care for the patient
- Provides grief support and counseling to the patient as well as the surviving family and friends for up to 13 months after death
- Makes short-term inpatient care available when pain or symptoms become too difficult to manage at home, or the caregiver needs respite time
- Delivers special services like speech and physical therapy, when needed

Location of Care

The majority of hospice care is provided in the place the patient calls home. In addition to private residences, this includes nursing homes, assisted living facilities, and residential facilities. Hospice care may also be provided in freestanding hospice facilities and hospitals (see Location of Care).

Levels of Care

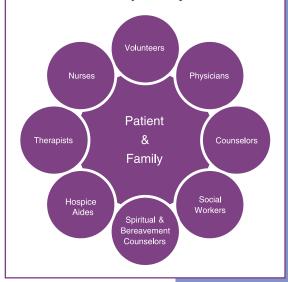
Hospice patients may require differing intensities of care during the course of their illness. While hospice patients may be admitted at any level of care, changes in their status may require a change in their level of care. The Medicare Hospice Benefit affords patients four levels of care to meet their clinical needs: routine home care, continuous home care, inpatient respite care, and general inpatient care. Payment for each covers all aspects of the patient's care related to the terminal illness, including all services delivered by the interdisciplinary team, medication, medical equipment, and supplies.

- Routine Home Care (RHC) is the most common level of hospice care. With this type of care, an individual has elected to receive hospice care at their residence.
- Continuous Home Care (CHC) is care provided for between eight and 24 hours a day to manage pain and other acute medical symptoms. CHC services must be

predominately nursing care, supplemented with caregiver and hospice aide services intended to maintain the terminally-ill patient at home during a pain or symptom crisis.

- Respite Care (also referred to as Inpatient Respite Care (IRC)) is available to provide temporary relief to the patient's primary caregiver. Respite care can be provided in a hospital, hospice facility, or a long-term care facility with enough 24-hour nursing personnel present.
- **General Inpatient Care (GIP)** is provided for pain control or other acute symptom management that cannot feasibly be provided in any other setting. GIP begins when other efforts to manage symptoms are not sufficient. GIP can be provided in a Medicare certified hospital, hospice inpatient facility, or nursing facility with a registered nursing available 24 hours a day to provide direct patient care.

Figure 1: Structure of the interdisciplinary team





Introduction (continued)

Volunteer Services

The U.S. hospice movement was founded by volunteers who continue to play an important and valuable role in hospice care and operations. Moreover, hospice is unique as it is the only Medicare benefit which requires volunteers to provide at least five percent of total patient care hours.

Hospice volunteers provide service in three general areas:

- Spending time with patients and families ("direct support")
- Providing clerical and other services to support patient care and clinical services ("clinical support")
- Engaging in a variety of activities such as fundraising, outreach and education, and serving on a hospice's board of directors (general support)

Bereavement Services

Counseling or grief support for the patient and their loved ones is an essential part of hospice care. After the patient's death, bereavement support is offered to families for at least one year. These services can take a variety of forms, including telephone calls, visits, written materials about grieving, phone or video calls, and support groups. Individual counseling may be offered by the hospice, or the hospice may make a referral to a community resource.

Some hospices also provide bereavement services to the community in addition to supporting patients and their families.

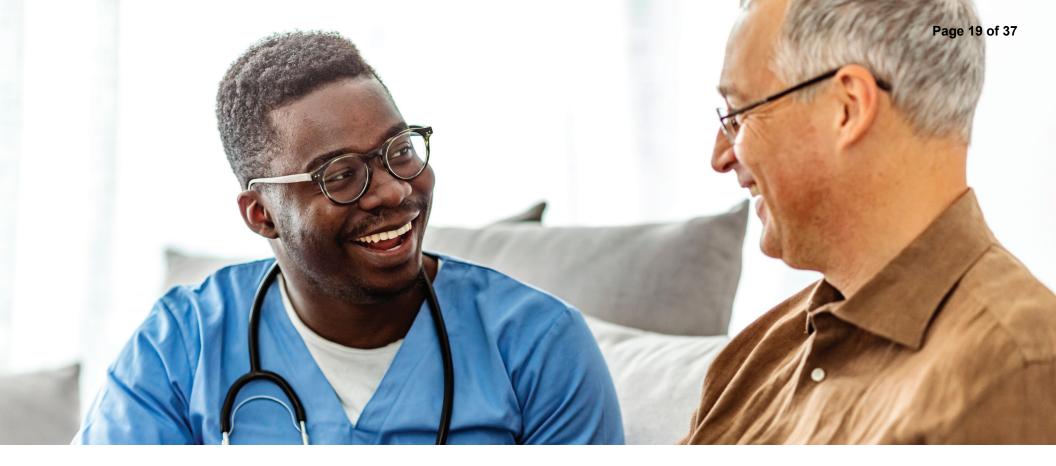
Quality of Care

In 2010, the Patient Protection and Affordable Care Act (ACA) mandated the initiation of a quality reporting program for hospices known as the Hospice Quality Reporting Program (HQRP). All Medicare-certified hospices must comply with HQRP reporting requirements; failure to comply results in a percentage point reduction to the Annual Payment Update (APU) for the corresponding fiscal year.

CMS determines the quality measures hospices must report and the processes they must use to submit data for those measures. In addition, data from HQRP measures are displayed on Care Compare, the official CMS website for publicly reported healthcare quality measures. Currently, the measures included in the HQRP are the Hospice Item Set Comprehensive Assessment Measure at Admission, Hospice Visits in Last Days of Life, the Hospice Care Index, and the CAHPS® Hospice Survey.

Veterans

The US Department of Veterans Affairs (VA) provides a hospice benefit as part of the VA Standard Medical Benefits Package. The hospice benefit can be delivered by VA or community providers wherever the enrolled Veteran calls home, including a personal residence, a nursing home, or an inpatient unit. Similar to the Medicare benefit, VA requires the Veteran to have a terminal condition with a prognosis of six months or less if the disease runs its normal course.



Introduction (continued)

Hospice care for Veterans can present unique challenges. Veterans may be facing illnesses intensified by health complications due to toxic exposures or traumatic events and experience a reemergence of traumatic life experiences due to end-of-life symptoms and may deny pain medication or other comfort measures. It is also common for Veterans to choose not to share their military experience with providers due to lack of identification as a Veteran, feelings of shame or guilt related to their service, and subscription to ideals of military stoicism. Each Veteran's experience varies greatly depending on the conflict they served in as well as their age, the location of their service, and their role in the conflict.

Hospice providers caring for Veterans can learn how to accompany and guide Veterans through their life stories towards a more peaceful ending through the <u>We Honor Veterans program</u> (WHV). WHV provides educational tools and resources to:

- Promote Veteran-centric educational activities
- Increase organizational capacity to serve Veterans
- Support development of strategic partnerships
- Increase access and improve quality of care for Veterans in the community

See <u>appendix</u> for details on methodology, limitations, and data sources, including cited references within the report.

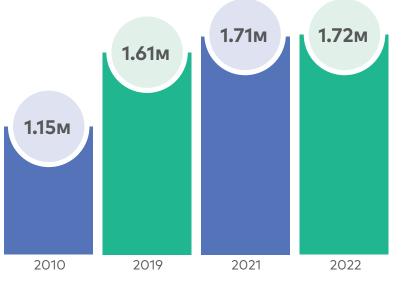
Section 2: Who Receives Hospice Care?

How many Medicare beneficiaries received care?

As seen in Figure 2, 1.72 million Medicare beneficiaries were enrolled in hospice care for one day or more in calendar year (CY) 2022. This is a slight increase from 2021 but approximately equal to 2020. This includes patients who:

- Died while enrolled in hospice
- Were enrolled in hospice in 2021 and continued to receive care in 2022
- Left hospice care alive during 2022 (live discharges)

Figure 2: Number of Medicare hospice users (millions of beneficiaries)

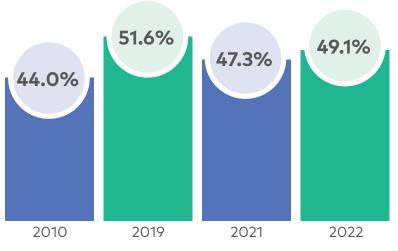


What proportion of Medicare decedents were served by hospice?

Of all Medicare decedents¹ in CY 2022, 49.1% received one day or more of hospice care and were enrolled in hospice at the time of death. This is the first increase in utilization since 2019. Utah had the highest hospice utilization by Medicare decedents (59.61%) and Puerto Rico had the lowest utilization (21.36%

1. Decedents refers to Medicare beneficiaries who have died.

Figure 3: Share of Medicare decedents who used hospice (percentage)



Source: MedPac March 2024 Report to Congress, Table 9-2

Source: MedPAC July Data Book, 11-8

Figure 4: Share of Medicare decedents who used hospice, by state

State	Hospice Beneficiaries	Hospice Utilization	State	Hospice Beneficiaries	ι
UT	15,126	59.61%	IL	58,605	
FL	150,304	55.97%	NV	16,332	
RI	6,528	55.14%	TN	40,753	
WI	36,900	54.31%	MA	32,395	
IA	20,029	54.24%	VA	40,524	
AZ	45,760	54.08%	PA	72,087	
DE	6,656	54.02%	NM	11,339	
ОН	78,330	52.87%	MD	25,195	
тх	145,160	52.23%	СТ	16,100	
MN	29,696	52.09%	NJ	37,709	
ID	10,152	51.83%	CA	176,754	
SC	35,137	51.81%	HI	6,692	
KS	17,968	51.78%	VT	3,359	
ME	9,375	50.62%	SD	3,927	
МІ	60,241	49.74%	MS	19,010	
IN	38,740	49.47%	WV	11,914	
OR	23,325	49.28%	КҮ	22,823	
со	24,528	49.03%	WA	29,761	
GA	55,622	48.70%	МТ	4,937	
AL	37,003	48.59%	WY	2,222	
NC	58,146	48.57%	ND	2,642	
NE	9,560	48.43%	VI	384	
LA	27,533	48.19%	AK	1,299	
МО	36,933	47.79%	DC	1,561	
ОК	26,620	47.77%	NY	48,618	
NH	7,663	47.18%	PR	10,278	
AR	19,659	47.09%	Source: Hospice Analy	<i>t</i> :	

Hospice Jtilization 46.62% 46.25% 46.09% 46.05% 45.74% 45.41% 45.08% 44.88% 44.58% 43.99% 43.98% 43.77% 43.36% 42.85% 42.56% 42.15% 41.44% 40.96% 39.43% 37.71% 36.24% 33.11% 30.34% 27.15% 26.34% 21.36%

What percent of hospice patients were enrolled in Medicare Advantage within the year?

In CY 2022, Medicare Advantage (MA) continued growing into a larger portion of the Medicare population, as seen in Figure 5. A vast majority of MA beneficiaries shift to Traditional Medicare to utilize the Medicare Hospice Benefit. A small sect of beneficiaries who stay with MA for hospice care have value-based insurance design (VBID) plans.

As demonstrated in Figure 6, utilization of the hospice benefit remains slightly higher among decedents enrolled in MA plans than among Traditional Medicare users. Both MA and Traditional Medicare utilization increased from CY 2021 but have yet to return to pre-COVID-19 utilization rates.

Figure 5: Medicare Advantage v. Traditional Medicare beneficiaries (in millions)

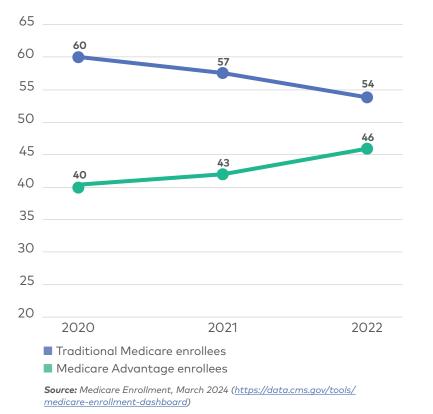
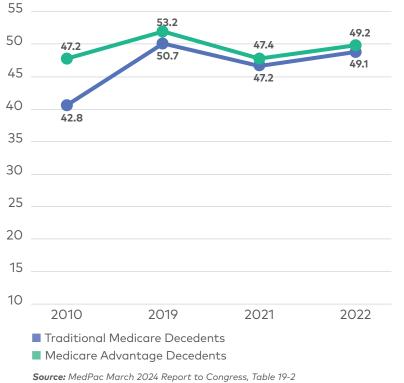


Figure 6: Medicare Advantage v. Traditional Medicare hospice use (percentage)



What are the characteristics of Medicare beneficiaries who received hospice care?

Medicare Beneficiary and Decedent Characteristics

In CY 2022, approximately 2.6 million Medicare (both Traditional and Medicare Advantage) beneficiaries died which includes both the 1.72 million who elected hospice care and those who did not use hospice. When reviewing hospice specific demographic information, it is necessary to understand the larger population of Medicare beneficiaries and decedents as detailed in Table 1 below.

Table 1: CY 2022 Medicare beneficiaries and decedents, by characteristics

Demographic Characteristic	Total Medicare Enrollees	Decedents
Total	67,990,335	2,649,240
Age		
Under 65 Years	11,718,703	234,301
65-74 years	33,199,315	672,663
75-84 Years	16,930,722	834,527
85-94 years	5,497,522	735,523
95 years and Over	644,073	172,226
Sex		
Male	31,087,927	1,310,409
Female	36,902,396	1,338,831
Race		
Non-Hispanic White	52,870,608	2,162,178
Black (or African-American)	7,333,277	285,289
Asian/Pacific Islander	1,930,681	50,400
Hispanic	2,346,723	66,708
American Indian/Alaska Native	266,193	13,047
Other	1,425,135	42,852
Unknown	1,817,718	28,766

Source: Hospice Analytics

Beneficiary Gender

In CY 2022, when presented with a binary question, beneficiaries who identified as female and died in 2022, 54.3% used hospice. Among beneficiaries who identified as male and died in 2022, 43.8% used hospice. Both groups saw an increase of utilization from 2021 to 2022 greater than the average change from 2010 to 2021.

Figure 7: Share of Medicare decedents who use hospice, by gender

Among Medicare decedents who identified as female

54.3% used hospice (2022)

Among Medicare decedents who identified as male



Source: MedPac March 2024 Report to Congress, Table 9-2

This section refers to shares of decedents which is calculated as:

number of beneficiaries in the group who both died and received hospice

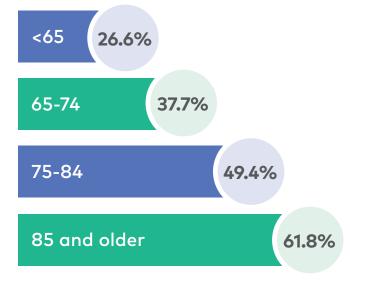
total number of beneficiaries in the group who died

This calculation compares how each group accesses hospice but does not compare size of the groups or health disparities or inequities factors which can impact the those who access Medicare.

Beneficiary Age

In CY 2022, as shown in Figure 8, 61.8% of Medicare decedents age 85 years and older utilized the Medicare Hospice Benefit, while progressively smaller percentages of decedents in younger age groups received hospice care. Figure 9 highlights the overall increase for all ages groups from CY 2021 to 2022, but utilization has yet to return to pre-COVID-19 rates.

Figure 8: Share of Medicare decedents who used hospice, by age 2022 (percentage)



Source: MedPAC March 2024 Report to Congress, Table 9-2

Figure 9: Share of Medicare decedents who used hospice, by age 2010-22 (percentage)



Source: MedPAC March 2024 Report to Congress, Table 9-2

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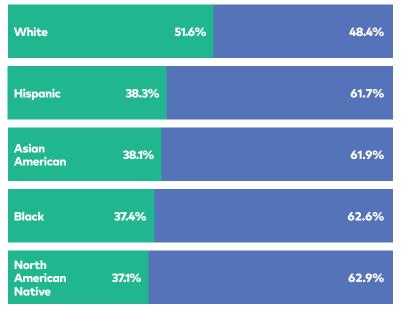
Who Receives Hospice Care? (continued)

Beneficiary Race/Ethnicity

In CY 2022, 51.6% of White Medicare decedents used the Medicare Hospice Benefit. 38.1% of Asian American Medicare decedents, and 37.4% of Black Medicare decedents enrolled in hospice. 38.3% of Hispanic and 37.1% of North American Native Medicare decedents used hospice in 2022.

Figure 10: Share of Medicare decedents who used hospice, by race

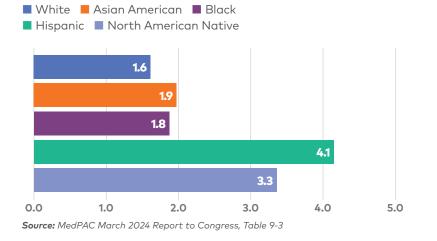
- Medicare Decedents who utilized hospice
- Medicare Decedents who did not utilized hospice



Source: MedPAC March 2024 Report to Congress, Table 9-3

CY 2022 saw an increase in hospice utilizations by all race/ ethnicity groups with Hispanic beneficiaries seeing the largest increase. No group has returned to pre-COVID-19 utilization.

Figure 11: Percentage change of decedents who use hospice from 2021 to 2022, by race



Beneficiary Location

In CY 2022, decedent beneficiaries located in an urban area were the only group with over half of decedents using hospice (50.2%); whereas, rural (44.9%, 39.8%) and frontier (33.0%) decedent beneficiaries have much lower rates of utilization. Despite multiple rural classifications, rural decedents near an urban community are more similar to urban decedents. whereas rural decedents not near an urban community have a utilization rate more similar to frontier decedents. However, all groups saw a similar percentage point change from 2021 to 2022 (1.7% to 2.9%).

Figure 12: Share of Medicare decedents who use hospice, by location

Urban	50.2%
Micropolitan	47.2%
Rural, adjacent to urban	47.8%
Rural, nonadjacent to urba	n 42.1%
Frontier	35.2%

Source: MedPAC March 2024 Report to Congress, Table 9-2

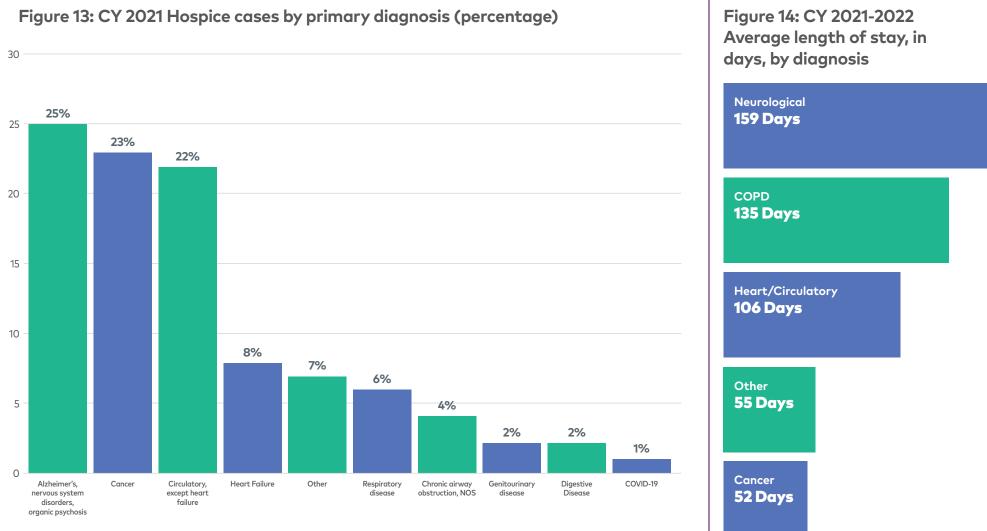
Principal Diagnosis

The principal hospice diagnosis is the diagnosis (based on ICD-10 codes) determined to be the most contributory to the patient's terminal prognosis. Alzheimer's/nervous system disorders/organic psychosis (25%) is the top category of diagnosis for hospice beneficiaries and appears multiple times in the top diagnoses by, ICD-10 code. Cancer and circulatory diseases round out the top three diagnoses groups which account for nearly three-fourths of all hospice beneficiary diagnoses. Although COVID-19 accounts for only 1% of primary diagnoses, it may still have been a secondary or contributory diagnosis.

Table 2: CY 2022 Top 20 Principal Hospice Diagnoses, by ICD-10 code

Rank		ional Classification of Diseases, Tenth Revision (ICD-10)/ d Principal Diagnosis"	Number of Beneficiaries	Percentage of all Reported Principal Diagnoses
1	G311	Senile degeneration of brain, not elsewhere classified	132,665	7.7
2	G309	Alzheimer's disease, unspecified	115,336	6.7
3	J449	Chronic obstructive pulmonary disease, unspecified	74,178	4.3
4	G301	Alzheimer's disease with late onset	61,097	3.5
5	G20	Parkinson's disease	50,977	2.9
6	1509	Heart failure, unspecified	46,806	2.7
7	12510	Atherosclerotic heart disease of native coronary artery w/o angina pectoris	43,159	2.5
8	1672	Cerebral atherosclerosis	42,583	2.5
9	C3490	Malignant neoplasm of unspecified part of unspecified bronchus or lung	40,948	2.4
10	1110	Hypertensive heart disease with heart failure	36,776	2.1
11	1679	Cerebrovascular disease, unspecified	35,699	2.1
12	E43	Unspecified severe protein-calorie malnutrition	32,976	1.9
13	1130	Hypertensive heart & chronic kidney disease with heart failure and stage 1-4 or unspecified chronic kidney disease	32,194	1.9
14	1639	Cerebral infarction, unspecified	27,188	1.6
15	C61	Malignant neoplasm of prostate	26,676	1.5
16	N186	End stage renal disease	23,695	1.4
17	J9601	Acute respiratory failure with hypoxia	22,129	1.3
18	C259	Malignant neoplasm of pancreas, unspecified	21,678	1.3
19	J441	Chronic obstructive pulmonary disease w (acute) exacerbation	18,992	1.1
20	C189	Malignant neoplasm of colon, unspecified	18,372	1.1

As seen in Figure 13, patients with a neurological primary diagnosis have the longest average length of stay (159 days) followed by chronic obstructive pulmonary disease (COP) with 135 days. All diagnoses saw increases from 2021 except for COP with a decrease of five days.



Note: NOS (not otherwise specified). Cases include all patients who received hospice care in 2022, not just decedents. "Diagnosis" reflects primary diagnosis on the beneficiary's last hospice claim in 2022. Subgroups may not sum to 100 percent due to rounding.

Source: MedPAC July 2024 Data Book, Chart 11-13

Source: MedPAC July 2024 Data Book, Chart 11-15; MedPAC July 2023 Data Book, Chart 11-14

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Section 3: How Much Care Is Received?

Length of Stay

The average lifetime length of stay (LOS) for Medicare decedents enrolled in hospice in 2022 was 95.3 days; an increase from 2021 which saw a decrease after a large increase in 2020. The median lifetime length of stay (MLOS) was 18 days which is a return to the norm.

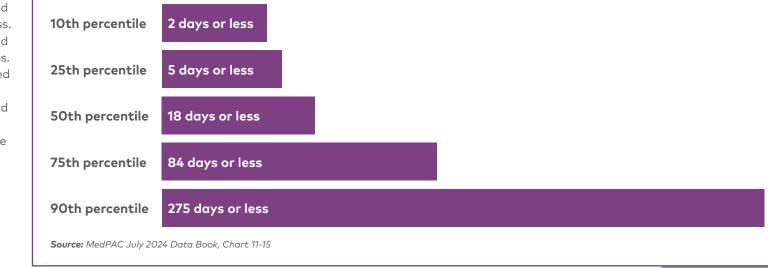
Table 3: Average lifetime length of stay, in days

Year	Average lifetime length of stay among decedents (in days)	Median lifetime length of stay among decedents (in days)	Number of Medicare decedents who used hospice (in millions)
2010	87.0	18	0.87
2019	92.5	18	1.20
2021	92.1	17	1.29
2022	95.3	18	1.30

Note: "Lifetime length of stay" is calculated for decedents who were using hospice at the time of death or before death and reflects the total number of days the decedent was enrolled in the Medicare hospice benefit during their lifetime.

Source: MedPAC March 2024 Report to Congress, Table 9-3

Figure 15: CY 2021 days of care by length of stay, in days



Days of Care by Length of Stay in 2022

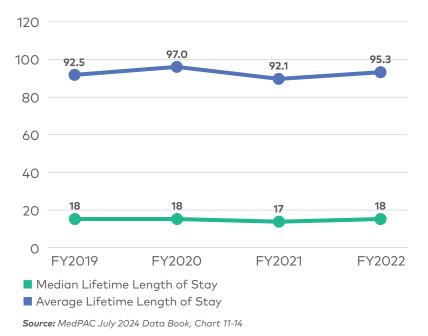
- 10% of patients were enrolled in hospice for two days or less.
- 25% of patients were enrolled in hospice for five days or less.
- 50% of patients were enrolled for 18 days or less.
- 75% of patients were enrolled for 84 days or less.
- The top 10% of patients were enrolled for more than 275 days.

How Much Care Is Received? (continued)

Days of Care

Figure 16 depicts the variation in length of stay between median and average lifetime (includes all elections of hospices). The difference in the median and the average shows how despite some patients having very long lengths of stay (due to a variety of factors), most patients have a short length of stay on hospice.

Figure 16: Average lifetime lengths of stay and median lifetime lengths of stay, in days, FY 2019 - 2022



Discharges

In CY 2022, 17.3% of all Medicare hospice discharges were live, which was flat from 2021 and at the pre-COVID-19 level. Only discharges for moving out of services saw an increase in 2022.

Table 4: Rates of hospice live discharge and reported reason for discharge, CY 2020–2022 (percentage)

Reason for Discharge	2020	2021	2022		
All live discharges	15.4%	17.2%	17.3%		
Patient-Initiated Live Discharges					
Revocation	5.7	6.3	6.1		
Transferred hospice providers	2.2	2.4	2.4		
Hospice-Initiated Live Discharges					
No longer terminally ill	5.6	6.3	6.1		
Moved out of service area	1.6	2.0	2.3		
Discharged for cause	0.3	0.3	0.3		

Source: MedPAC July 2024 Data Book, Chart 11-19

How Much Care Is Received? (continued)

Location of Care

Average length of stay by location of care, as shown in Figure 17, was 98 days at a private residence, 109 days in nursing facilities, and 165 days in assisted living facilities. Median length of stay by location of care, shown in Figure 18, was 25 days at a private residence, 22 days in nursing facilities, and 55 days in assisted living facilities. The variance between average and median lengths of stay indicates that although some patients have long lengths of stay, most patients have short hospice stays.

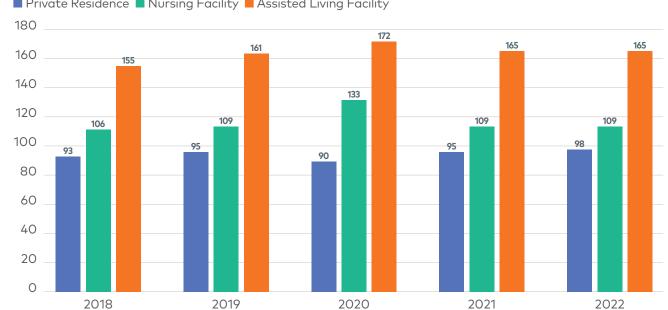
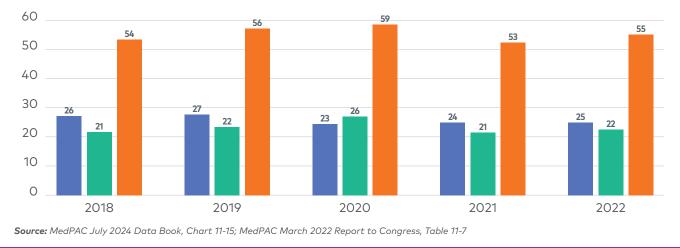


Figure 17: Average length of stay by location of care, in days

Private Residence Nursing Facility Assisted Living Facility

Figure 18: Median days by location of care, in days

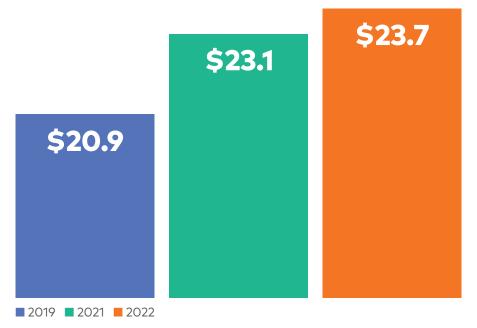
Private Residence Nursing Facility Assisted Living Facility



Section 4: How Does Medicare Pay for Hospice?

Medicare paid hospice providers a total of \$23.7 billion dollars for care provided in CY 2022, representing an increase of 2.7% over the previous year. This is slower growth compared to 2019-2021 but similar growth from 2020-2021.

Figure 19: Medicare spending (billions of US dollars)



Source: MedPAC March 2024 Report to Congress, Table 9-3

Spending by Level of Care

In CY 2022, the vast majority of Medicare days of care were at the routine home care (RHC) level of care for both payments made and days of care provided.

Table 5: Percent of payment, by level of care

Percent of Payment by Level of Care	Total payment (in billions)	Percentage of payment
Routine home care	21.55	93.78%
General inpatient care	1.14	4.96%
Inpatient respite care	0.15	0.67%
Continuous home care	0.14	0.60%

Table 6: Percent of days, by level of care

Percent of Days by Level of Care	Total number of days (in millions)	Percentage of day
Routine home care	128.32	98.78%
General inpatient care	1.14	0.88%
Inpatient respite care	0.35	0.27%
Continuous home care	0.09	0.07%

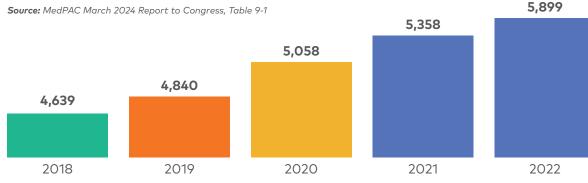
Source: Hospice Analytics

Section 5: Who Provides Care?

How many hospices were in operation in 2021?

In CY 2022, there were 5,899 Medicare certified hospices in operation based on claims submitted. This is an increase of over 500 hospices since 2021 and outpaced the average annual percent change since 2018.

Figure 20: Number of operating Medicare certified hospices



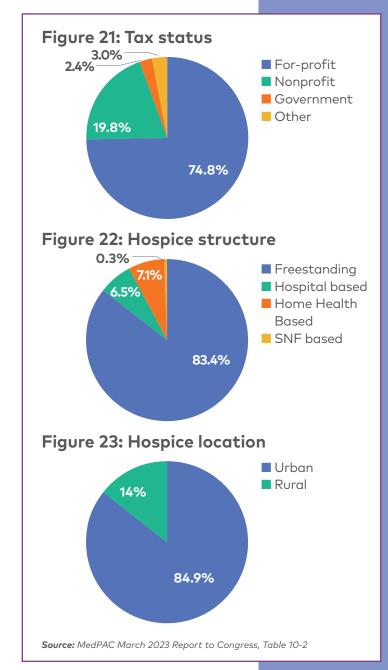
What are the characteristics of Medicare certified hospices?

As shown in Table 7, the growth in hospice ownership in CY 2022 is being driven by the growth in for-profit (10.1%), freestanding (9.0%), and urban providers (11.1%). The largest decreases were with nonprofit (-2.2%), hospital based (-3.3%), and rural providers (-2.1%).

Table 7: Characteristics of Medicare certified hospices

Category	2020	2021	2022	Percent change 2018–2021	Percent change 2021–2022
For profit	3691	4008	4414	7.4%	10.1%
Nonprofit	1220	1195	1169	-1.4%	-2.2%
Government	146	143	141	-3.5%	-1.4%
Freestanding	4189	4511	4919	6.8%	9.0%
Hospital based	413	396	383	-4.4%	-3.3%
Home health based	437	434	421	-2.1%	-3.0%
SNF based	19	17	17	-8.2%	0.0%
Urban	4196	4505	5006	6.2%	11.1%
Rural	853	845	827	-1.0%	-2.1%

Source: MedPAC March 2024 Report to Congress, Table 9-1



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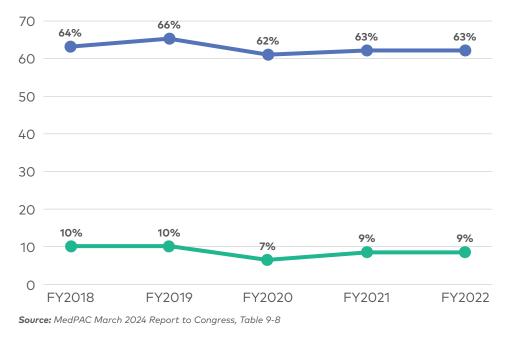
Section 6: What is the Quality of Hospice Care?

Scores on publicly reported quality measures were generally stable in the most recent reporting period. Scores for the Hospice Item Set Comprehensive Assessment Measure increased slightly, while scores for the ten components of the composite Hospice Care Index show 15% of providers with publicly available data were outliers on three or more measures, and 2% were outliers on five or more.

Visits in the last days of life by both nurses and social workers were steady in CY 2022 but continue to remain below pre-COVID-19 levels, and performance continues to vary widely among providers. Hospice Visits in Last Days of Life measures the percentage of patients who received a visit from a registered nurse or social worker on at least two of the last three days of life. Scores from providers who met criteria for public reporting of the measure vary from a 25th percentile of 40% to a 75th percentile of 75%.

Figure 24: Share of days with visits in last seven days of life (percentage)

- Share of days with nurse visits in last 7 days of like
- Share of days with social worker visits in last 7 days of life



The CAHPS® survey assesses the experiences of patients who died while receiving hospice care and their primary informal caregivers. The CAHPS Hospice Survey provides Hospice Survey Star Ratings for hospices with at least 75 survey responses in a reporting period.

In the most recently available data (January 2021 – December 2022), 50.0% of participating providers received four or five stars on the CAHPS® (Consumer Assessment of Healthcare Providers and Systems) survey, which represents a 1% increase over the prior reporting period. However, Star Ratings were available for fewer than half of providers (2,046). Survey data from the same reporting period shows that 81% of caregivers rated the hospice as a 9 or 10 out of 10, and 84% said they would definitely recommend the hospice.

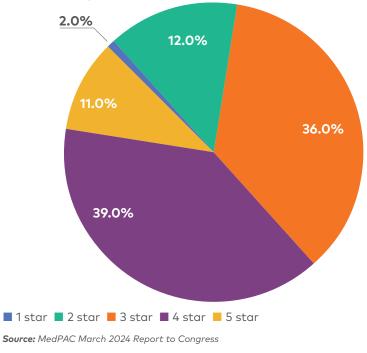


Figure 25: Breakdown of hospice star ratings (percentage)

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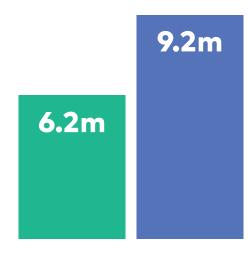
Special Focus: Veterans

In FY 2023, the Veterans Administration (VA) paid for 48,194 Veterans to receive home hospice care from VA contracted providers compared to 13,316 from community providers. This was a substantial decrease for both VA and community providers since FY 2022. With roughly half of all living US Veterans enrolled in the Veterans Health Administration (VHA) and only 5% of Veteran deaths occurring in VHA facilities, this figure is limited in summarizing the full breadth of US Veterans receiving end-of-life care.

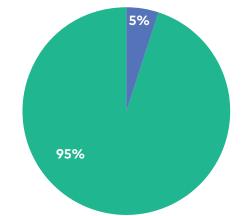
Figure 26: Veterans' Use of VHA (in millions)

Figure 27: Deaths in VHA facilities

Enrolled in VHAReceived Care from VHA



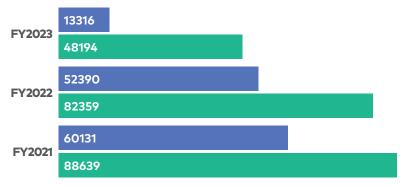
Source: Congressional Budget Office. The Veterans Community Care Program: Background and Early Effects. October 2021. Washington, D.C. Deaths in VHA Facility
 No Deaths in VHA Facility



Source: O'Malley, Kelly A. PhD; Baird, Lola MSW; Kaiser, Anica Pless PhD; Bashian, Hannah M. PhD, MEd; Etchin, Anna G. PhD, RN; Sager, Zachary S. MD; Heintz, Hannah BA; Korsun, Lynn BA; Kemp, Katherine; Moye, Jennifer PhD. Maximizing Veterans Health Affairs Community Hospice Collaborations: Review of Perceived Resource Needs to Support Veterans at End of Life. Journal of Hospice & Palliative Nursing 26(1):p 21-28, February 2024. Page 34 of 37

Figure 28: VA funded hospice patients, by location

Community Providers VA Facilities

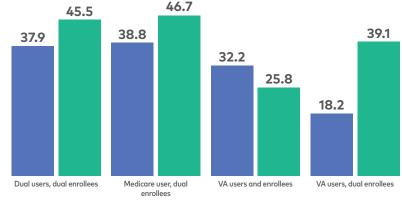


Source: U.S. Department of Veterans Affairs FY 2023, FY 2024, and FY 2025 Budget Submissions

Veterans can be eligible for both Medicare and VA health benefits; dually eligible Veterans have the right to elect either Medicare or VA as the payer to cover hospice care, and can use both or just one. Between FY 2010 and FY 2014, Veteran decedents who were enrolled in both but used only Medicare had the highest utilization rate, followed by Veteran decedents who were enrolled in both and used both.

Figure 29: Hospice utilization, by type of enrollee

Death in FY2007-2008 Death in FY2010-2014



Source: U.S. Department of Veterans Affairs FY 2023, FY 2024, and FY 2025 Budget Submissions

Special Focus: Veterans (continued)

In FY 2023, the VA paid \$165.80 million for home hospice care, a substantial increase from FY 2022 (\$21.52 million). The number of visits and cost per visit increased in FY 2023 as well.

Table 8: VA payments for Hospice

	FY 21	FY 22	FY 23
Payments	\$30,977,000	\$21,521,000	\$165,795,000
Clinical encounter/visit	577,064	460,876	727,350
Cost per clinic stops/procedures	\$53.62	\$46.70	\$227.94

Source: U.S. Department of Veterans Affairs FY 2023, FY 2024, and FY 2025 Budget Submissions

Figure 30 VA hospice funding, by location

■ VA Facilities ■ Community Providers



Note: The reason for the large increase in funding and clinical encounter is unclear based on the VA budget documents.

Source: U.S. Department of Veterans Affairs FY 2023, FY 2024, and FY 2025 Budget Submissions

Appendix

Citations

CMS Program Statistics - Medicare Deaths

Congressional Budget Office. The Veterans Community Care Program: Background and Early Effects. October 2021. Washington, D.C.

Hospice Analytics

MedPAC March 2024 Report to Congress, Chapter 9: Hospice services

MedPAC July 2024 Data Book, Section 11: Other services

Miller SC, Intrator O, Scott W, Shreve ST, Phibbs CS, Kinosian B, Allman RM, Edes TE. Increasing Veterans' Hospice Use: The Veterans Health Administration's Focus On Improving End-Of-Life Care. Health Aff (Millwood). 2017 Jul 1;36(7):1274-1282. doi: 10.1377/hlthaff.2017.0173. PMID: 28679815.

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VA President's Budget Request – FY 2023, 2024, and 2025 Budget Submissions

Limitations

For this report, only sources with comprehensive national level claims data were utilized. More detailed information may be available but did not include all Medicare hospice claims for the time period of this report's review.

In addition, data reported may be in calendar year (January through December) or fiscal year (October through September).

Finally, the data utilized is limited by the format of data collected by the Centers for Medicare and Medicaid Services; specifically, the limited language describing gender and race/ethnicity.

Questions May Be Directed To:

National Alliance for Care at Home Attention: Communications Phone: 703.837.1500 Web: www.AllianceForCareAtHome.org

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