

Hospice Services	Pg
Service Category Definition – DSHS State Services	1
PowerPoint: 2022 Hospice Chart Review Update, TRG	5
Providing Care and Comfort at the End of Life – National Institute on Aging, November 2022	7
Facts and Figures Hospice Care in America – National Hospice and Palliative Care Organization, 2023 Edition, revised December 2023	13

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:	<p>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.</p> <p>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:</p> <ul style="list-style-type: none"> • Room • Board • Nursing care • Mental health counseling, to include bereavement counseling • Physician services • Palliative therapeutics <p>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.</p>
Local Service Category Definition:	<p>Hospice services encompass palliative care for terminally ill PLWH 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.</p> <p>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.</p>
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,

	<p>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.</p> <p>Allowable Ryan White/State Services funded services are:</p> <ul style="list-style-type: none"> • Room • Board • Nursing care • Mental health counseling, to include bereavement counseling • Physician services • Palliative therapeutics <p>Services NOT allowed under this category:</p> <ul style="list-style-type: none"> • 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:	<p>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.</p> <p>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.</p> <p>Services must be provided by a medically directed interdisciplinary team, qualified in treating individual requiring hospice services.</p>

	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:	<p>These services must be:</p> <ul style="list-style-type: none"> 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. <p>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.</p>

FY 2025 RWPC “How to Best Meet the Need” Decision Process

Step in Process: Council		Date: 06/13/2024
Recommendations:	Approved: Y: _____ No: _____ Approved With Changes: _____	If approved with changes list changes below:
1.		
2.		
3.		
Step in Process: Steering Committee		Date: 06/06/2024
Recommendations:	Approved: Y: _____ No: _____ Approved With Changes: _____	If approved with changes list changes below:
1.		
2.		
3.		
Step in Process: Quality Improvement Committee		Date: 05/14/2024
Recommendations:	Approved: Y: _____ No: _____ Approved With Changes: _____	If approved with changes list changes below:
3.		
2.		
3.		
Step in Process: HTBMTN Workgroup #3		Date: 04/17/2024
Recommendations:	Financial Eligibility:	
1.		
2.		
3.		

Hospice

NOT REVIEWED IN 2020

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.

2022 Monitoring

This year all subrecipients will be monitored, remotely if possible and in-person if necessary.

The monitoring period will cover calendar year 2021



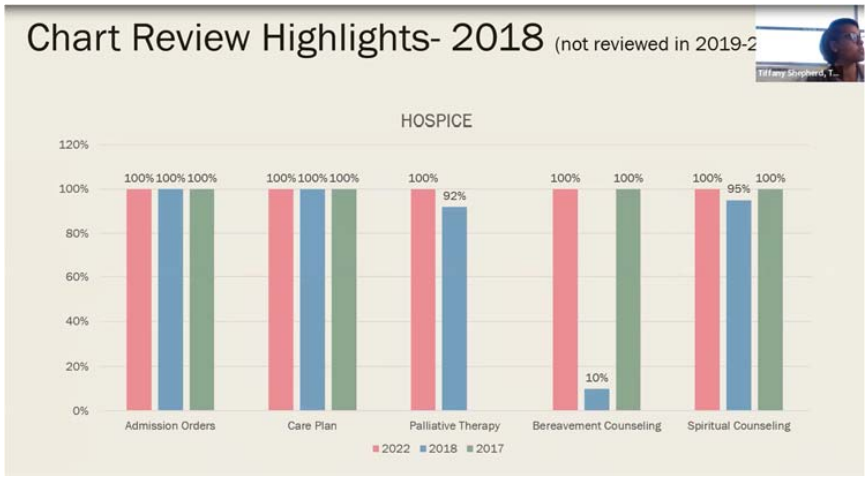
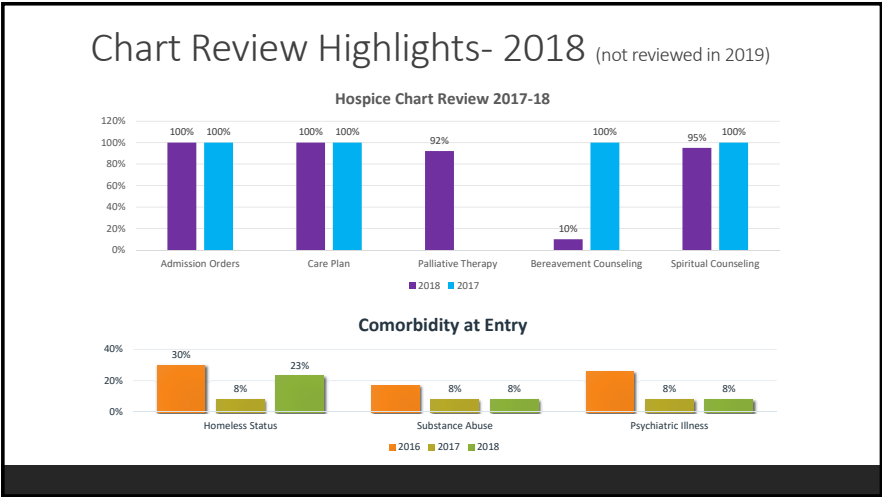
Special chart review process is being evaluated for the RW Planning Council process during the "odd" years DSHS is not requiring monitoring (requires DSHS approval)

Description of Service

Hospice services encompass palliative care for terminally ill clients and support services for clients and their families. Services are provided by a licensed nurse and/or physical therapist.

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.



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 [cognitive function](#) 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: [physical comfort](#), [mental and](#)



[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 [What Are Palliative Care and Hospice Care?](#)).

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 [skin](#) 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, [constipation](#), 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 depressed 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 [dying person who has been confused](#) 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](#)

[the caregiver](#). 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, [ask for help when you need it](#) 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.



NHPCO Facts and Figures

2023 EDITION

Published December 2023

Table of Contents

Please see the Data Sources Section at the end of this report for details on the data sources used within this publication.

Section 1: Introduction	1		
About this Report	1	Days of Care	13
Impact of COVID-19	1	Discharges	13
What is hospice care?	1	Location of Care	14
How is hospice care delivered?	1		
What services are provided?	2	Section 4: How Does Medicare Pay for Hospice?	15
Location of Care	2	Spending by Level of Care	15
Levels of Care	2		
Volunteer Services	3	Section 5: Who Provides Care?	16
Bereavement Services	3	How many hospices were in operation in 2021?	16
Quality of Care	4	What are the characteristics of Medicare certified hospices?	16
Medicare Advantage Value-Based Insurance Design (VBID)	4		
		Section 6: What is the Quality of Hospice Care?	17
Section 2: Who Receives Hospice Care?	5	Special Focus: Value-Based Insurance Design (VBID)	18
How many Medicare beneficiaries received care?	5		
What proportion of Medicare decedents were served by hospice?	5	Appendix	19
What percent of hospice patients were enrolled in Medicare Advantage within the year?	6	Citations	19
What are the characteristics of Medicare beneficiaries who received hospice care?	7	Limitations	19
		Questions May Be Directed To Suggested Citation	19
			19
Section 3: How Much Care Is Received?	12		
Length of Stay	12		
Days of Care by Lifetime Length of Stay in 2020	12		





The findings in this report reflect only those patients who received care through 2021, provided by the hospices certified by the Centers for Medicare and Medicaid Services (CMS) and reimbursed under the Medicare Hospice Benefit.

Section 1: Introduction

About this Report

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

- Hospice patient characteristics
- Location 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 continues to see the impact of COVID-19 on patient care and the effect of the COVID-19 waivers on the traditional delivery of hospice care. These waivers included increased telehealth services. 2020 saw decreases in hospice usage in many areas due to the number of deaths outpacing hospice use ([see Section 3](#)).

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. Hospices 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 hospice services.

How is hospice care delivered?

Typically, a loved one 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

Introduction (continued)

additional care or other services. Hospice staff are on-call 24 hours a day, seven days a week.

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 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

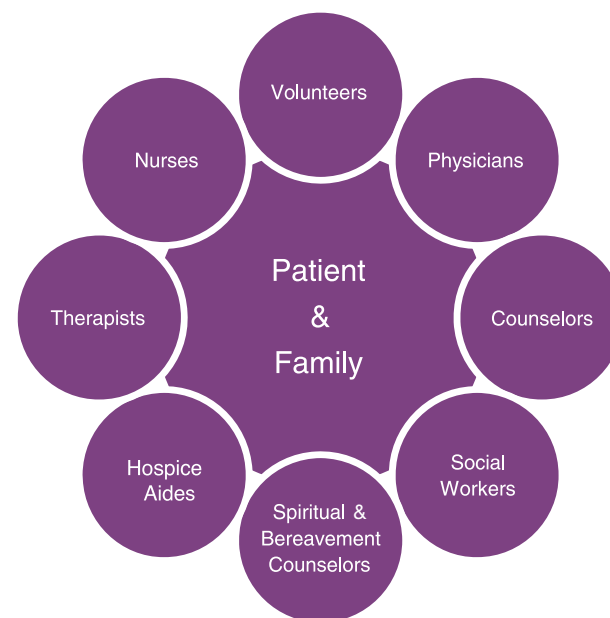
The majority of hospice care is provided in the place the patient calls home. In addition to private residences, this includes nursing homes, assisted living facilities, and residential facilities. Hospice care may also be provided in freestanding hospice facilities and hospitals (see Levels of Care).

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.

Figure 1: Structure of the interdisciplinary team



Introduction (continued)

- **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.

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 provider 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.





Introduction (continued)

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.

Medicare Advantage Value-Based Insurance Design (VBID)

The Medicare Advantage (MA) value-based insurance design (VBID) is a model with the goal of providing innovation, more choices, and high-quality, person-centered care to Medicare beneficiaries. The hospice benefit component (sometimes referred to as the hospice carve-in) in MA plans participating in VBID must include palliative care and transitional concurrent care in addition to hospice services. The palliative and concurrent care eligibility and services are designed by each MA organization. The Hospice Benefit component began in 2021 and is currently set to end in 2030.

See [appendix](#) for details on methodology, limitations, and data sources, including cited references within the report.

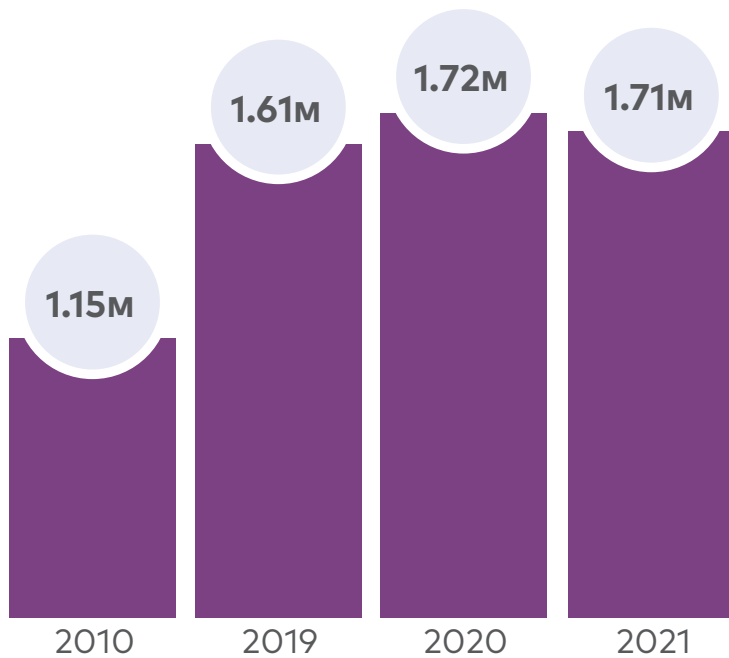
Section 2: Who Receives Hospice Care?

How many Medicare beneficiaries received care?

As seen in Figure 2, 1.71 million Medicare beneficiaries were enrolled in hospice care for one day or more in calendar year (CY) 2021. This is flat from 2020. This includes patients who:

- Died while enrolled in hospice
- Were enrolled in hospice in 2020 and continued to receive care in 2021
- Left hospice care alive during 2021 (live discharges)

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



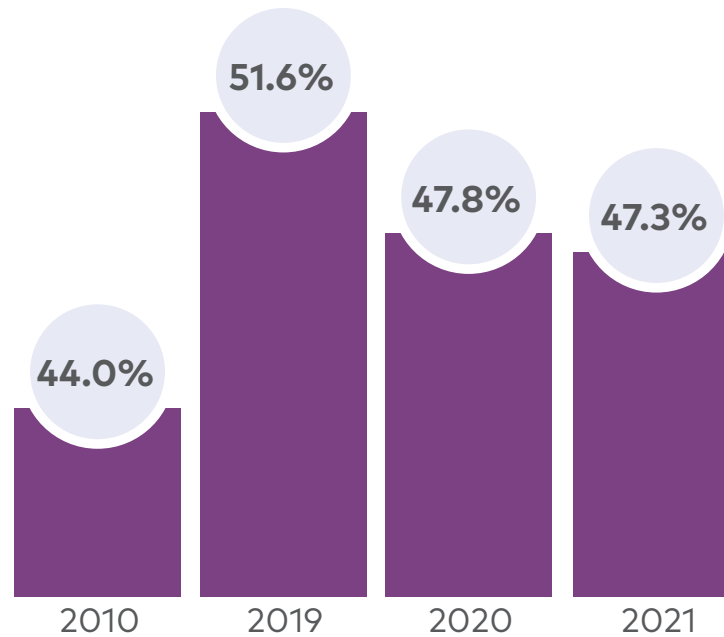
Source: MedPAC March 2023 Report to Congress, 10-4

What proportion of Medicare decedents were served by hospice?

Of all Medicare decedents¹ in CY 2021, 47.3% received one day or more of hospice care and were enrolled in hospice at the time of death. This continues the downward trend from 2020. This decrease was likely due to death continuing to outpace the growth in hospice due to COVID-19.

¹ Decedents refers to Medicare beneficiaries who have died.

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



Source: MedPac March 2023 Report to Congress, Table 10-3

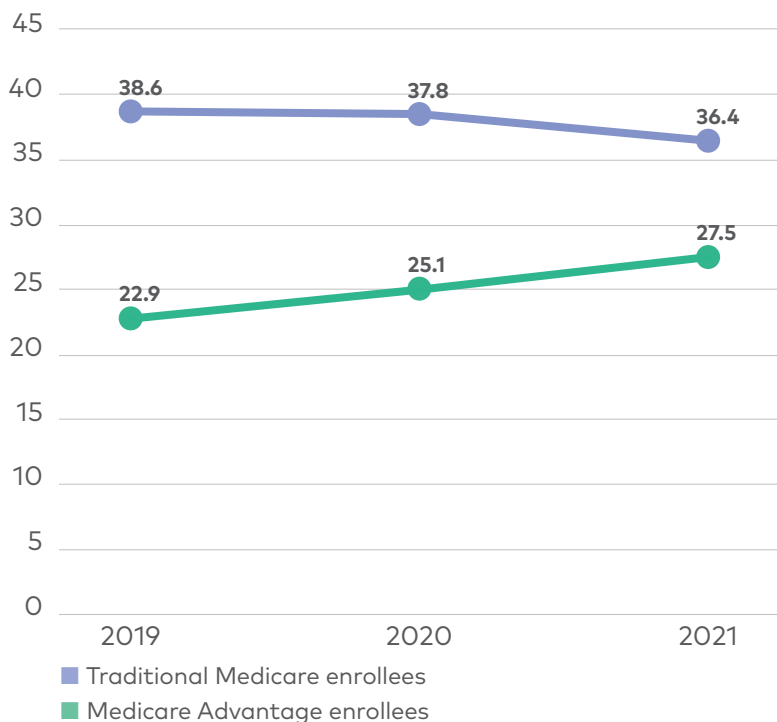
Who Receives Hospice Care? (continued)

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

In CY 2021, Medicare Advantage (MA) continued growing into a larger portion of the Medicare population as seen in Figure 4. To access hospice, MA beneficiaries must be in a value-based insurance design (VBID) plan or shift to Traditional Medicare to utilize the Medicare Hospice Benefit. Most beneficiaries switch to Traditional Medicare.

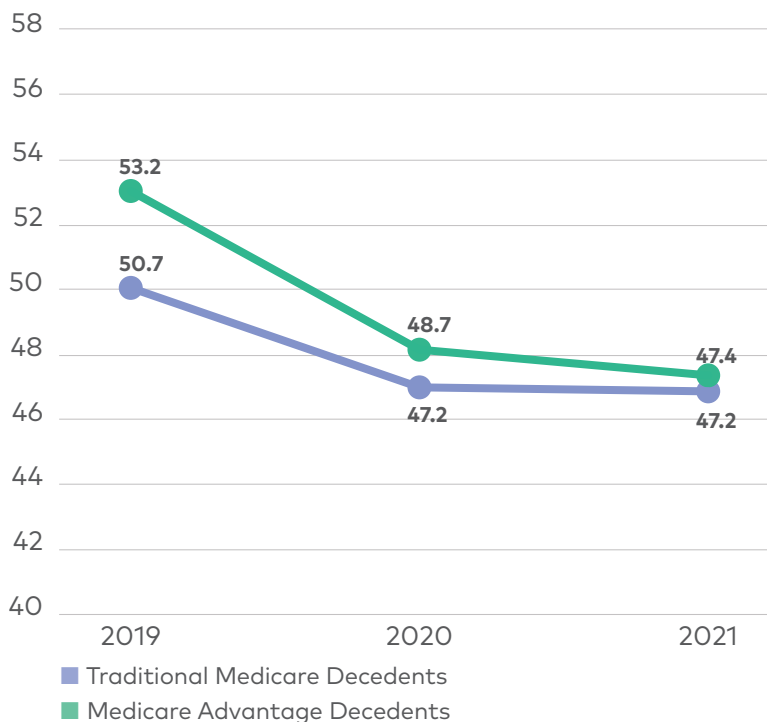
As demonstrated in Figure 5, utilization of the hospice benefit remains slightly higher among decedents originally enrolled in MA plans than among Traditional Medicare users. However, the percentage of MA beneficiaries utilizing hospice decreased (-1.3 percentage point) while Traditional Medicare beneficiaries were flat from CY 2020.

Figure 4: Medicare Advantage v. Traditional Medicare beneficiaries (in millions)



Source: Medicare Enrollment, June 2023
 (<https://data.cms.gov/tools/medicare-enrollment-dashboard>)

Figure 5: Medicare Advantage v. Traditional Medicare hospice use (percentage)



Source: MedPac March 2023 Report to Congress, Table 10-3

Who Receives Hospice Care? (continued)

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

Medicare Beneficiary and Decedent Characteristics

In CY 2021, approximately 2.8 million Medicare (both Traditional and Medicare Advantage) beneficiaries died which includes both the 1.7 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 2021 Medicare beneficiaries and decedents, by characteristics

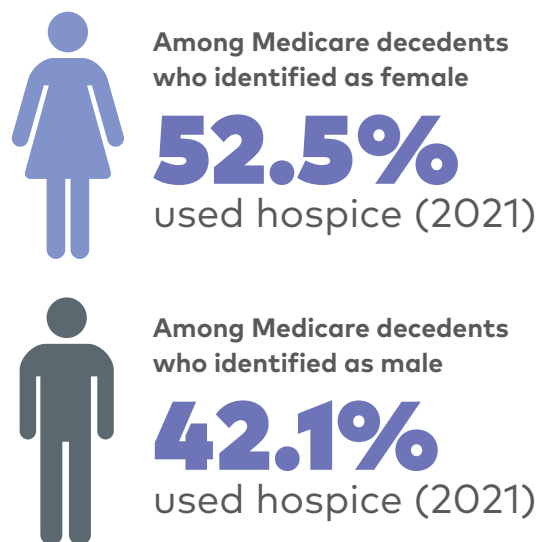
Demographic Characteristic	Total Medicare Enrollees	Decedents
Total	63,892,626	2,750,141
Age		
Under 65 Years	8,041,304	236,041
65-74 years	31,812,889	712,518
75-84 Years	17,379,347	843,160
85-94 years	5,908,242	765,942
95 years and Over	750,844	192,480
Sex		
Male	29,159,084	1,373,655
Female	34,733,542	1,376,486
Race		
Non-Hispanic White	46,504,697	2,088,893
Black (or African-American)	6,716,021	301,423
Asian/Pacific Islander	2,349,223	69,294
Hispanic	6,222,827	234,121
American Indian/Alaska Native	258,058	14,993
Other	546,619	19,574
Unknown	1,295,182	21,843

Source: CMS Program Statistics - Medicare Deaths

Beneficiary Gender

In CY 2021, when presented with a binary question, beneficiaries who identified as female and died in 2021, 52.5% used hospice. Among beneficiaries who identified as male and died in 2021, 42.1% used hospice. Both groups saw a drop in usage of less than one percentage point from 2020.

Figure 6: Share of Medicare decedents who use hospice, by gender



Source: MedPac March 2023 Report to Congress, Table 10-3

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

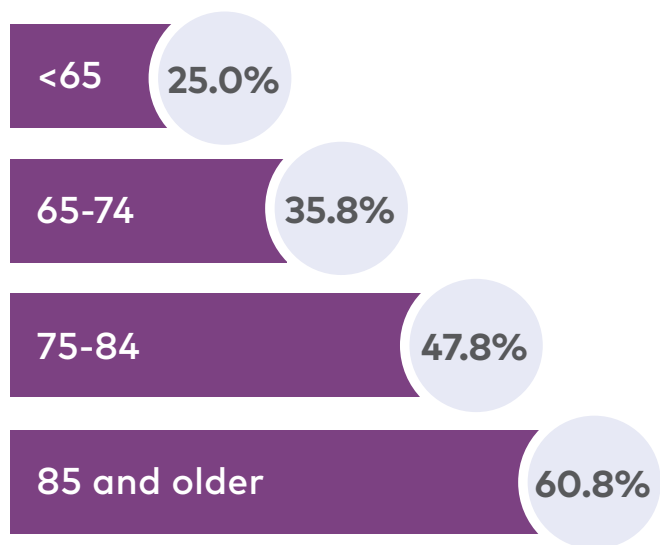
This calculation compares how each group accesses hospice but does not compare size of the groups or health disparities or inequities factors which can impact the those who access Medicare.

Who Receives Hospice Care? (continued)

Beneficiary Age

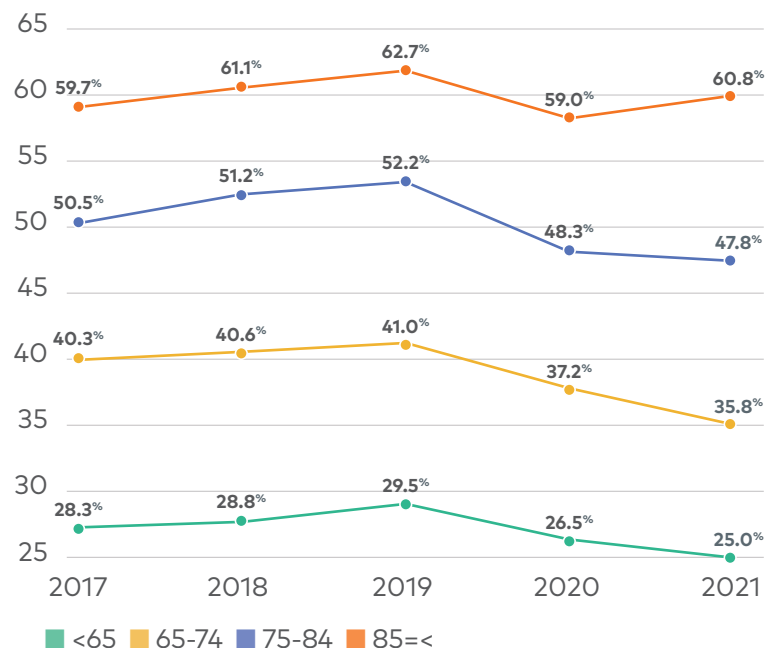
In CY 2021, as shown in Figure 7, 60.8% of Medicare decedents age 85 years and older utilized the Medicare Hospice Benefit, while progressively smaller percentages of decedents in younger age groups received hospice care. Figure 8 highlights beneficiaries over 85 were the only age group who saw an increase in usage in CY 2021, but no age group has returned to pre-COVID-19 levels.

Figure 7: Share of Medicare decedents who used hospice, by age 2021 (percentage)



Source: MedPAC March 2023 Report to Congress, Table 10-3

Figure 8: Share of Medicare decedents who used hospice, by age 2017-21 (percentage)



Source: MedPAC March 2023 Report to Congress, Table 10-3 & MedPAC March 2022 Report to Congress, Table 11-3

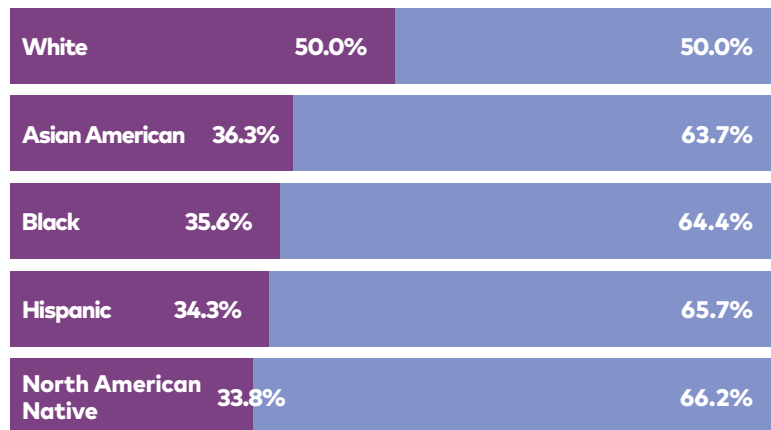
Who Receives Hospice Care? (continued)

Patient Race/Ethnicity

In CY 2021, 50.0% of White Medicare decedent beneficiaries used the Medicare Hospice Benefit. 36.3% of Asian American Medicare decedent beneficiaries and 35.6% of Black Medicare decedent beneficiaries enrolled in hospice in 2021. 34.3% of Hispanic and 33.8% of North American Native Medicare decedents used hospice in 2021.

2. North American Native is an updated term for the previously used American Indian/Alaska Native.

Figure 9: Share of Medicare decedents who used hospice, by race

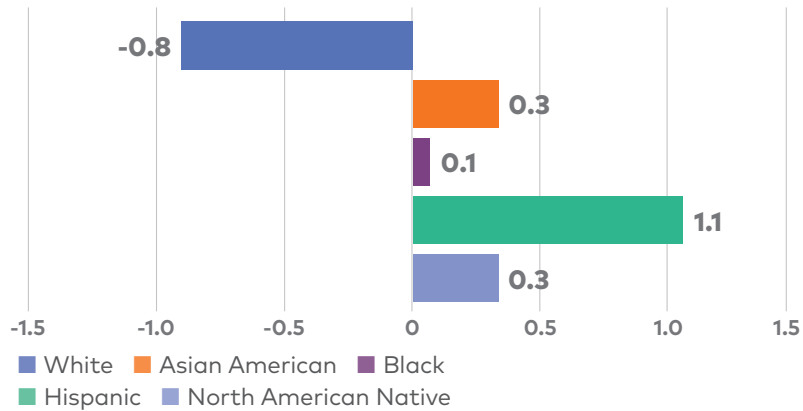


■ Medicare Decedents who utilized hospice
 ■ Medicare Decedents who did not utilize hospice

Source: MedPAC March 2023 Report to Congress, Table 10-3

CY 2021 saw an increase in hospice utilizations by all race/ethnicity groups except White beneficiaries which saw a -0.8 percentage point decrease. Despite this rebound from the 2020 decrease, no group has returned to pre-COVID-19 utilization percentages.

Figure 10: Percentage point change of decedents who use hospice, by race



Beneficiary Location

In CY 2021, a higher percentage of decedent beneficiaries located in an urban area (48.5%) utilized hospice compared to rural (44.9%, 39.8%) or frontier (33.0%) decedent beneficiaries. 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, micropolitan decedents saw the largest decrease from 2020 to 2021 (-1.7 percentage points).

Figure 11: Share of Medicare decedents who use hospice, by location



Source: MedPAC March 2023 Report to Congress, Table 10-3

Who Receives Hospice Care? (continued)

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. While cancer is in the top 20 diagnoses twice, it is tied with Alzheimer's/nervous system disorders/organic psychosis as the top category of diagnosis (24%). Although COVID-19 accounts for only 2% of primary diagnoses, it may still have been a secondary or contributory diagnosis.

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

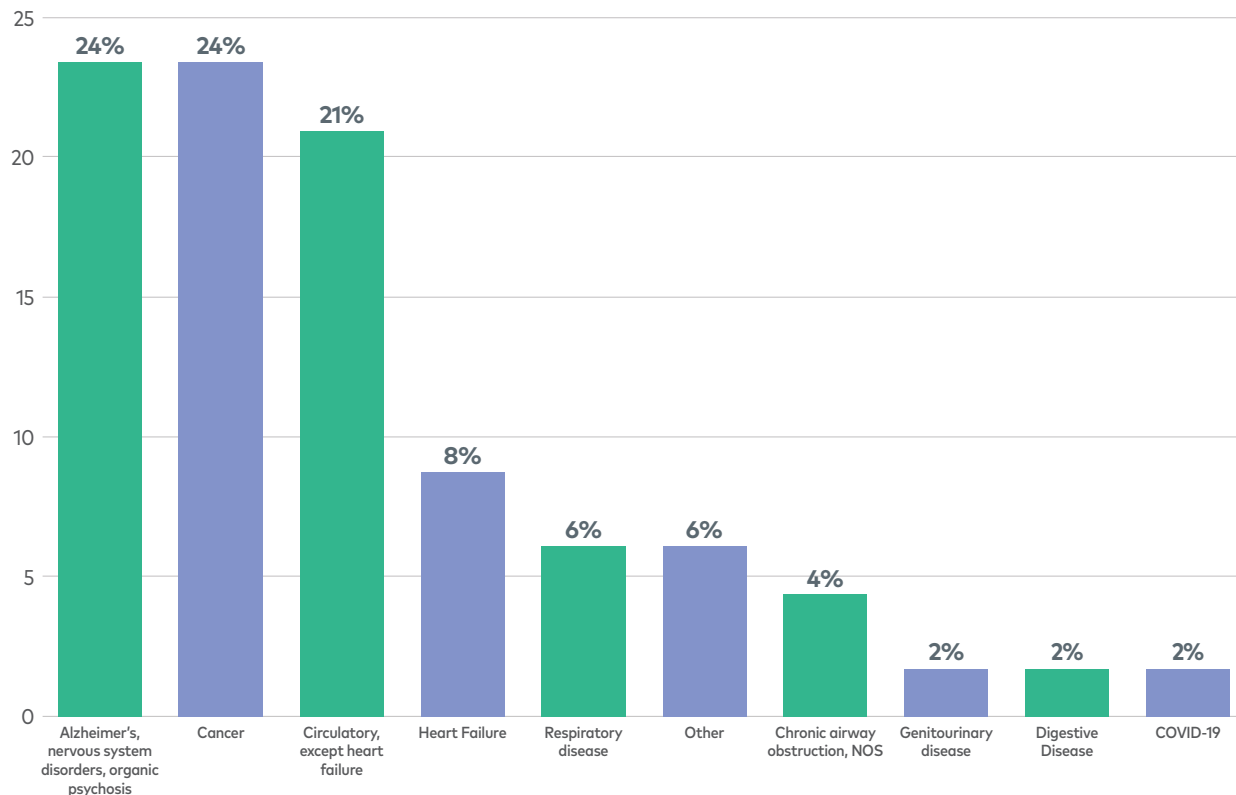
Rank	"International Classification of Diseases, Tenth Revision (ICD-10)/Reported Principal Diagnosis"	Number of Beneficiaries	Percentage of all Reported Principal Diagnoses
1	G30.9-Alzheimer disease, unspecified	135,910	7.4%
2	G31.1-Senile degeneration of brain, not elsewhere classified	124,365	6.8%
3	J44.9-Chronic obstructive pulmonary disease, unspecified	78,630	4.3%
4	G30.1-Alzheimer disease with late onset	63,980	3.5%
5	I50.9-Heart failure, unspecified	52,375	2.8%
6	G20-Parkinson disease	52,155	2.8%
7	"I25.10-Atherosclerotic heart disease of native coronary artery without angina pectoris"	47,117	2.6%
8	"C34.90-Malignant neoplasm of unspecified part of unspecified bronchus or lung"	44,093	2.4%
9	U07.1-Emergency use of U07.1	43,505	2.4%
10	I67.2-Cerebral atherosclerosis	38,543	2.1%
11	I11.0-Hypertensive heart disease with (congestive) heart failure	36,860	2.0%
12	I67.9-Cerebrovascular disease, unspecified	35,120	1.9%
13	E43-Unspecified severe protein-energy malnutrition	33,111	1.8%
14	I63.9-Cerebral infarction, unspecified	29,291	1.6%
15	"I13.0-Hypertensive heart and renal disease with (congestive) heart failure"	27,455	1.5%
16	C61-Malignant neoplasm of prostate	24,806	1.3%
17	N18.6-End stage renal disease	24,565	1.3%
18	J96.01-Acute respiratory failure with hypoxia	23,329	1.3%
19	C25.9-Malignant neoplasm: Pancreas, unspecified	22,128	1.2%
20	"J44.1-Chronic obstructive pulmonary disease with acute exacerbation, unspecified"	20,928	1.1%

Source: FY 2024 Hospice Wage Index and Quality Reporting Proposed Rule, Table 2

Who Receives Hospice Care? (continued)

As seen in Figure 13, patients with a neurological primary diagnosis have the longest average length of stay (155 days) followed by chronic obstructive pulmonary disease (COPD) with 140 days. While cancer is in the top 20 diagnoses twice, it is tied with Alzheimer's/nervous system disorders/organic psychosis as the top category of diagnosis (24%). Although COVID-19 accounts for only 2% of primary diagnoses, it may still have been a secondary or contributory diagnosis.

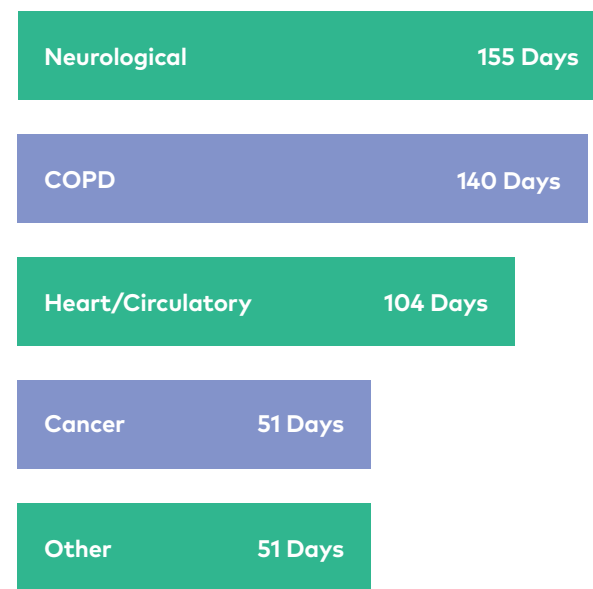
Figure 12: CY 2021 Hospice cases by primary diagnosis (percentage)



Note: Note: NOS (not otherwise specified). Cases include all patients who received hospice care in 2021, not just decedents. "Diagnosis" reflects primary diagnosis on the beneficiary's last hospice claim in 2021. Subgroups may not sum to 100 percent due to rounding.

Source: FY 2024 Hospice Wage Index and Quality Reporting Proposed Rule, Table 2

Figure 13: CY 2021 Average length of stay, in days, by diagnosis



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

Section 3: How Much Care Is Received?

Length of Stay

The average lifetime length of stay (LOS) for Medicare decedents enrolled in hospice in 2021 was 92.1 days; a decrease from 2020 which saw the highest increase in five years. The median lifetime length of stay (MLOS) was 17 days which is a decrease from the consistent 18 days over the last five years.

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	87.8	18	0.87
2019	92.5	18	1.20
2020	97.0	18	1.31
2021	92.1	17	1.29

Note: 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 2023 Report to Congress, Table 10-4

Days of Care by Lifetime Length of Stay in 2020

- 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 17 days or less.
- 75% of patients were enrolled for 79 days or less.
- The top 10% of patients were enrolled for more than 264 days.

Figure 14 CY 2021 days of care by length of stay, in days



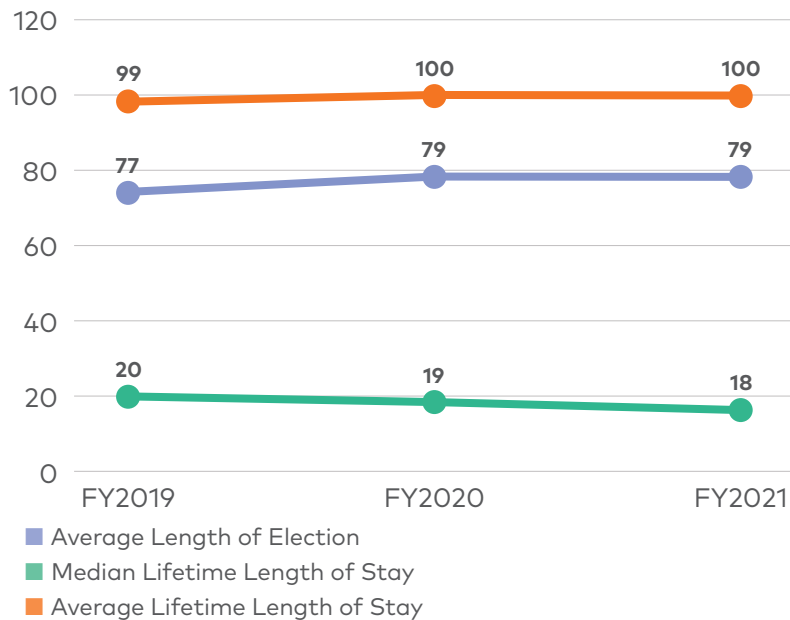
Source: MedPAC July 2023 Data Book, Chart 11-13

How Much Care Is Received? (continued)

Days of Care

Figure 15 depicts the variation in length of stay between median and average lifetime (includes all elections of hospices) and election (a patient may be included twice if they had multiple elections). 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 15: Average lifetime lengths of stay, average length elections, and median lifetime lengths of stay, in days



Source: FY 2024 Hospice Wage Index and Quality Reporting Proposed Rule, Table 4

Discharges

In CY 2021, 17.2% percent of all Medicare hospice discharges were live, which was a return to pre-pandemic level. All hospice discharges saw an increase in 2021 except for discharges for cause which did not change.

Table 4: Rates of hospice live discharge and reported reason for discharge, CY 2019–2021 (percentage)

Reason for Discharge	2019	2020	2021
All live discharges	17.4%	15.4%	17.2%
Patient-Initiated Live Discharges			
Revocation	6.5	5.7	6.3
Transferred hospice providers	2.3	2.2	2.4
Hospice-Initiated Live Discharges			
No longer terminally ill	6.5	5.6	6.3
Moved out of service area	1.7	1.6	2
Discharge for cause	0.3	0.3	0.3

Source: MedPAC July 2023 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 16 was 95 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 17, were 24 days at a private residence, 21 days in nursing facilities, and 53 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 16: Average length of stay by location of care, in days

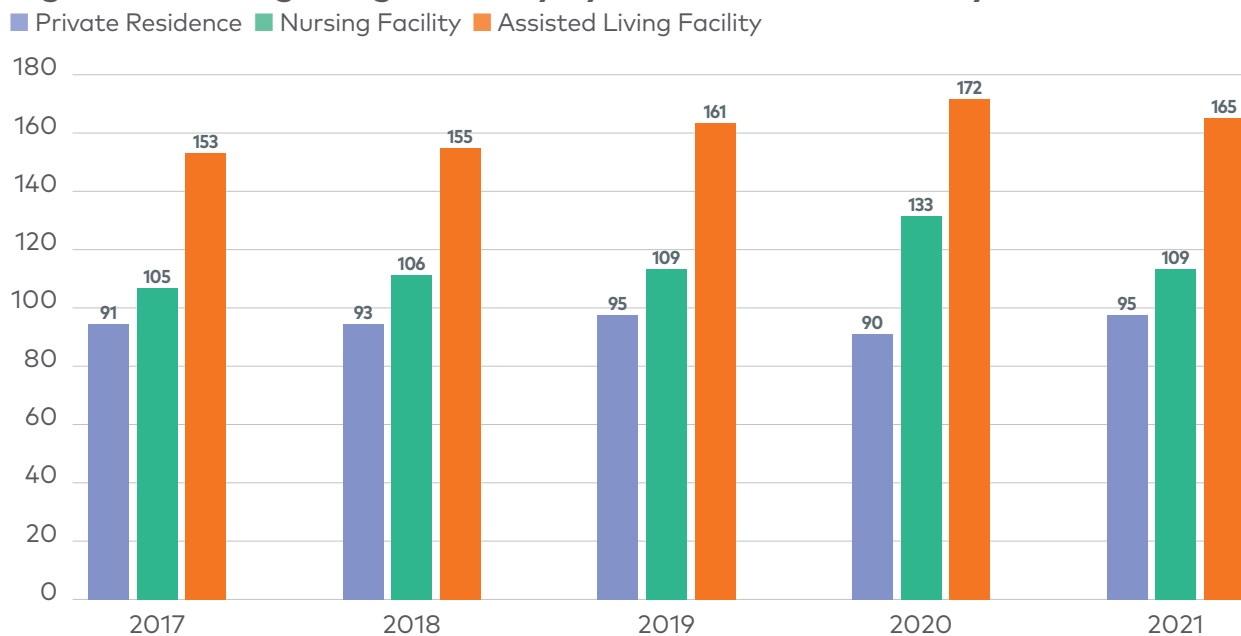
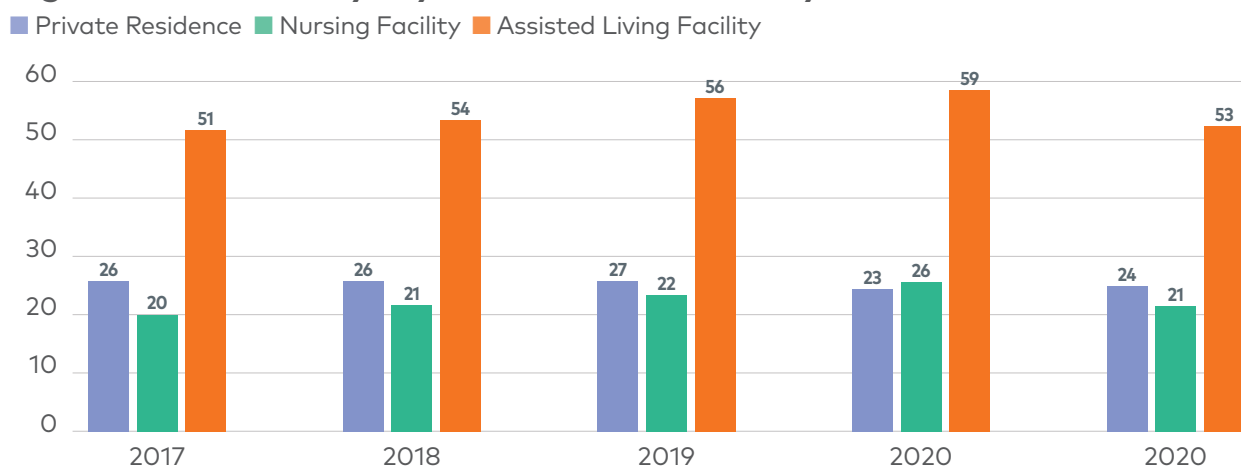


Figure 17: Median days by location of care, in days

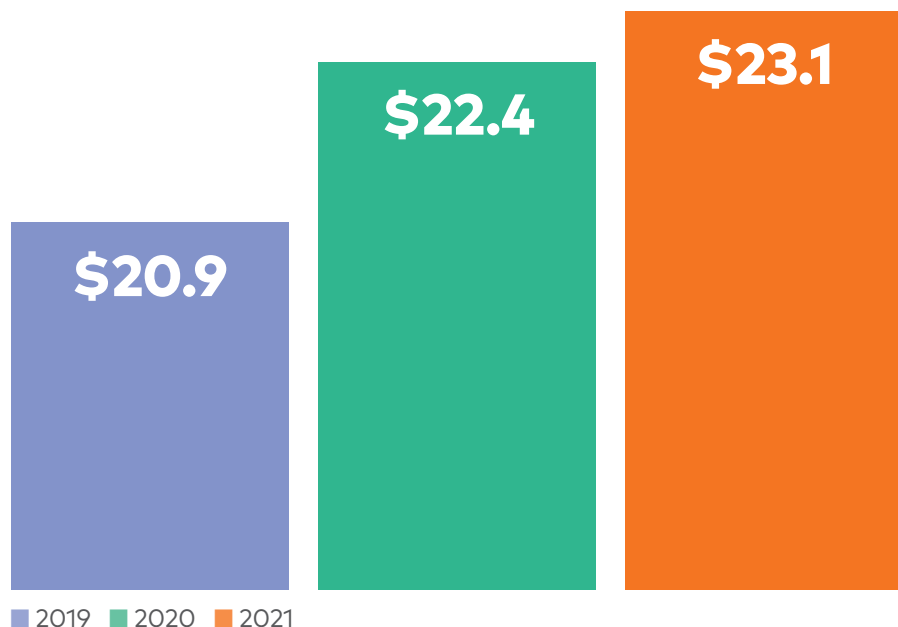


Source: MedPAC July 2023 Data Book, Chart 11-14; MedPAC March 2022 Report to Congress, Table 11-7

Section 4: How Does Medicare Pay for Hospice?

Medicare paid hospice providers a total of \$23.1 billion dollars for care provided in CY 2021, representing an increase of 2.8% over the previous year. This is slower growth compared to 2019-2020.

Figure 18 Medicare spending (billions of US dollars)



■ 2019 ■ 2020 ■ 2021

Source: MedPAC March 2023 Report to Congress, table 10-4

Spending by Level of Care

In FY 2022, the vast majority of Medicare days of care were at the routine home care (RHC) level of care for both percent of payments made and percent of days of care provided. The greatest change since FY 2013 is the decrease in both payments and days of continuous home care (CHC) and general inpatient (GIP); whereas, days and payments were stable for inpatient respite care.

Table 5: Percent of payment, by level of care

Percent of Payment by Level of Care	2013	2022
Routine home care	90.6%	93.7%
Continuous home care	1.8%	0.6%
Inpatient respite care	0.3%	0.7%
General inpatient care	7.3%	5.0%

Table 6: Percent of days, by level of care

Percent of Days by Level of Care	2013	2022
Routine home care	97.5%	98.8%
Continuous home care	0.4%	0.1%
Inpatient respite care	0.3%	0.3%
General inpatient care	1.8%	0.9%

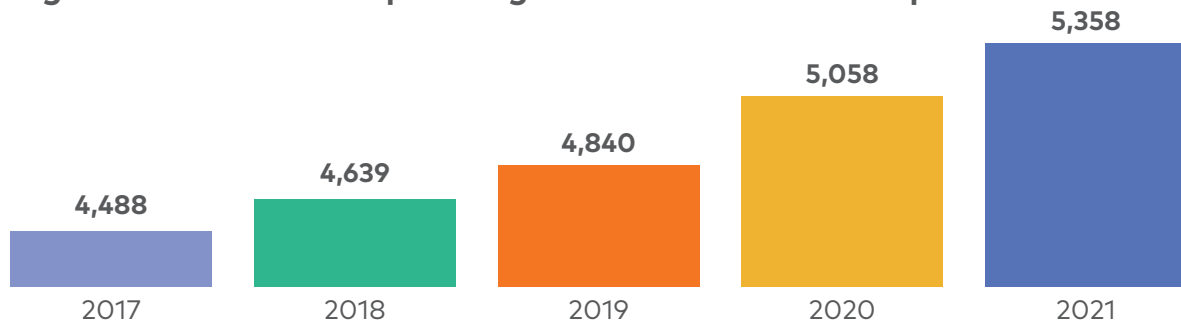
Source: FY 2024 Hospice Wage Index and Quality Reporting Proposed Rule, Table 3

Section 5: Who Provides Care?

How many hospices were in operation in 2021?

In CY 2021, there were 5,358 Medicare certified hospices in operation based on claims submitted. This is an increase of 300 hospices from 2020 and outpaced the average annual percent change since 2017.

Figure 19: Number of operating Medicare certified hospices



Source: MedPAC March 2023 Report to Congress, Table 10-2

What are the characteristics of Medicare certified hospices?

As shown in Table 7, the growth in hospice ownership in CY 2021 is being driven by the growth in for-profit (8.6%), freestanding (7.7%), and urban providers (7.4%). The largest decreases were with government (-2.1%), skilled nursing facility (SNF) based (-10.5%), and rural providers (-0.9%).

Table 7: Characteristics of Medicare certified hospices

Category	2020	2021	Percent change 2020–2021
For profit	3691	4008	8.6%
Nonprofit	1220	1195	-2.0%
Government	146	143	-2.1%
Freestanding	4189	4511	7.7%
Hospital based	413	396	-4.1%
Home health based	437	434	-0.7%
SNF based	19	17	-10.5%
Urban	4196	4505	7.4%
Rural	853	845	-0.9%

Source: MedPAC March 2023 Report to Congress, Table 10-2

Figure 20: Tax status

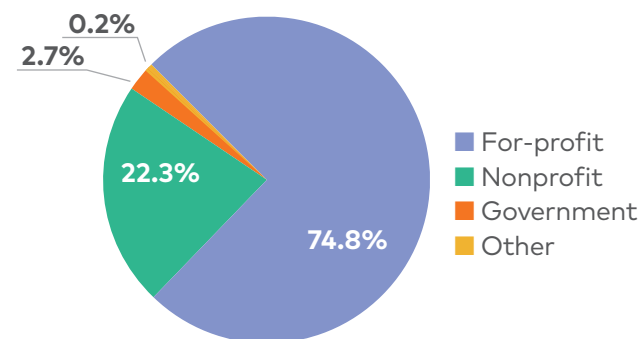


Figure 21: Hospice structure

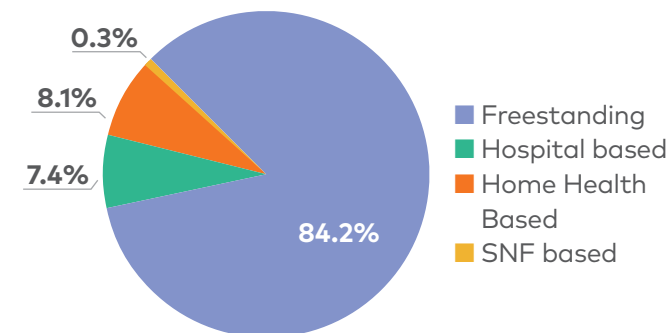
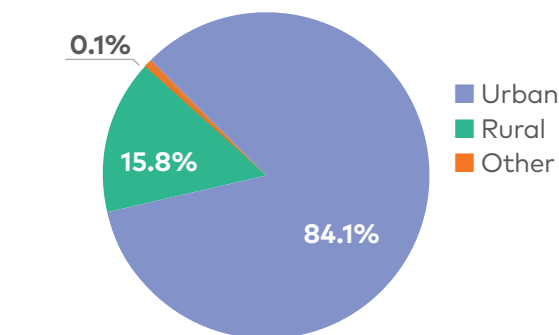


Figure 22: Hospice location

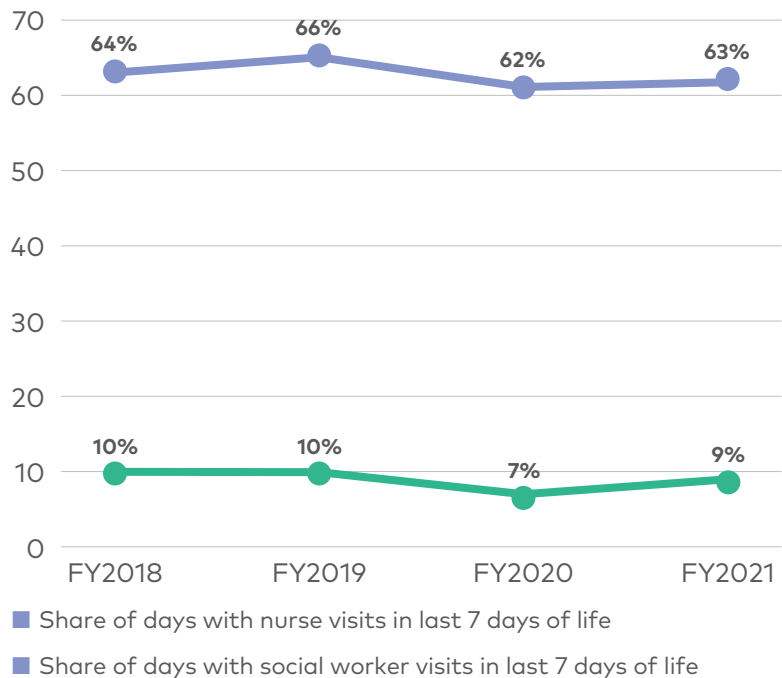


Source: MedPAC March 2023 Report to Congress, Table 10-2

Section 6: What is the Quality of Hospice Care?

CY 2021 saw an increase in visits in the last days of life by both nurses and social workers after a decline in 2020.

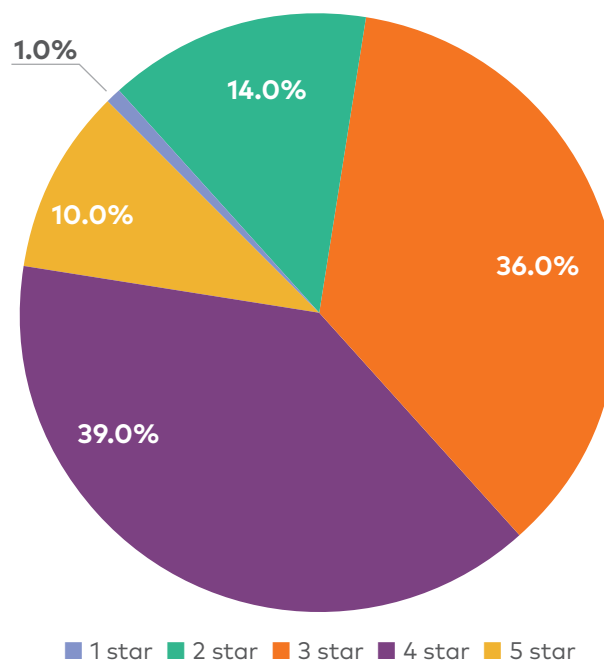
Figure 23: Share of days with visits in last seven days of life (percentage)



Source: MedPAC March 2023 Report to Congress, Table 10-9

In the most recently available data (April 2019-December 2019, July 2020-September 2021), 49.0% of participating providers received four or five stars on the CAHPS® (Consumer Assessment of Healthcare Providers and Systems) survey. The CAHPS® survey assesses the experiences of patients who died while receiving hospice care and their primary informal caregivers.

Figure 24: Breakdown of hospice star ratings (percentage)



Source: MedPAC March 2023 Report to Congress, Table 10-8

Special Focus: Value-Based Insurance Design (VBID)

Value-based insurance design (VBID) is a CMS Innovation Center (CMMI) model with the goal of providing innovation, more choices, and high-quality, person-centered care to Medicare beneficiaries through Medicare Advantage (MA). Starting in 2021, MA plans could voluntarily add a hospice benefit to their VBID plans. VBID beneficiaries are not included in the data on beneficiaries who utilize the Traditional Medicare Hospice Benefit.

From CY 2021 to 2022, there was an increase in both participating providers and beneficiaries as well as an increase in the percentage of use of in-network providers.

Table 8: Participating hospice providers

Participating hospice providers	2021	2022
In network hospice providers	17%	22%
Out of network hospice providers	83%	78%
Total providers	596	1,168
VBID hospice beneficiaries	2021	2022
Beneficiaries who utilized in network hospices	37%	48%
Beneficiaries who utilized out of network hospices	63%	52%
Total beneficiaries	9,630	19,065

Source: CMS Value-Based Insurance Design Model, Findings at a Glance, 2021-2022

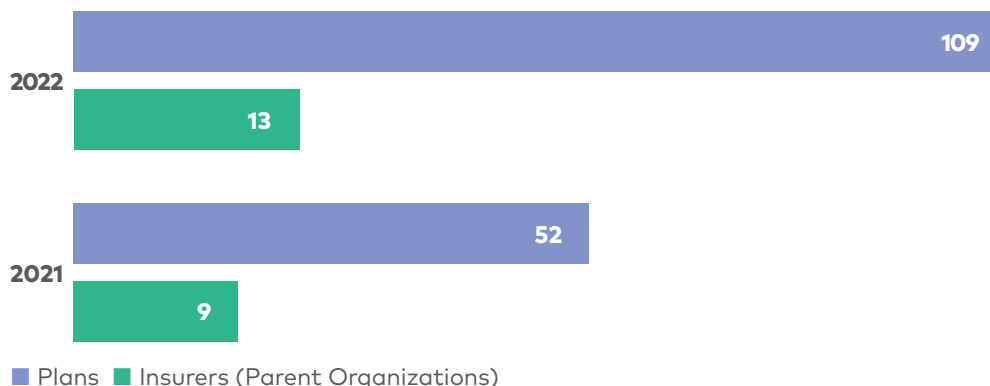
Table 9: VBID hospice beneficiaries

Characteristics	In Network Providers		Out of Network	
	#	%	#	%
For-profit	177	68.1%	655	68.1%
Nonprofit	58	22.3%	195	20.3%
Other	25	9.6%	93	9.7%
Rural	22	8.5%	83	8.6%
Non-rural	238	91.5%	879	91.4%

Source: CMS Value-Based Insurance Design Model, Findings at a Glance, 2021-2022

From CY 2021 to CY 2022, there was also an increase in the number insurers (MA parent organizations) and plans participating in VBID. However, some participating insurers and plans did not continue after 2021.

Figure 25: Medicare Advantage plan participation, CY 2021-2022



Source: CMS Value-Based Insurance Design Model, Findings at a Glance, 2021-2022

Appendix

Citations

[MedPAC March 2023 Report to Congress, Chapter 10: Hospice services](#)

[MedPAC July 2023 Data Book, Section 11: Other services](#)

[FY 2024 Hospice Wage Index and Quality proposed rule \(CMS-17787-9\)](#)

[MA VBID Model Phase II: Second Annual Evaluation Hospice At-A-Glance Report](#)

[CMS Program Statistics – Medicare Deaths](#)

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 Hospice and Palliative Care Organization

Attention: Communications

Phone: 703.837.1500

Web: www.nhpco.org/hospice-care-overview/hospice-facts-figures/

Email: Communications@nhpco.org

©2023 National Hospice and Palliative Care Organization.

All rights reserved, including the right to reproduce this publication or portions thereof in any form. Public use of this report and reported data is authorized if the National Hospice and Palliative Care Organization is clearly referenced.

Suggested Citation:

2023 Edition: Hospice Facts and Figures. Alexandria, VA: National Hospice and Palliative Care Organization.



NHPCO

National Hospice and Palliative
Care Organization

NHPCO

1731 King Street
Alexandria, VA 22314

tel. 703.837.1500 | nhpco.org

DECEMBER 2023