



NHPCO Facts and Figures

2021 EDITION

Published October 2021



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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
- Location and level of care
- Medicare hospice spending
- Hospice provider characteristics
- Volunteer and bereavement services

Currently, most hospice patients have their costs covered by Medicare, through the Medicare Hospice Benefit. The findings in this report reflect those patients who received care in 2019 provided by hospices certified by the Centers for Medicare 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 family as well.

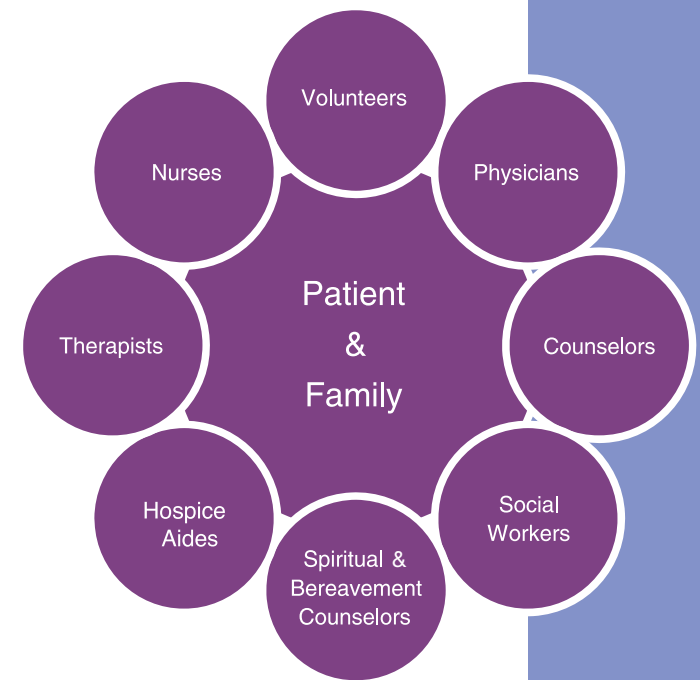
Hospice focuses on caring, not curing. In most cases, care is provided in the patient's private residence, but may also be provided in freestanding hospice facilities, hospitals, nursing homes, or other long-term care facilities. Hospice services are available to patients with any terminal illness. Hospices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

Introduction (continued)

How is hospice care delivered?

Typically, a family member serves as the primary caregiver for the patient 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 is on-call 24 hours a day, seven days a week.

The hospice team develops a care plan that meets each patient's individual needs for pain management and symptom control. This interdisciplinary team, 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; clergy or other spiritual counselors; trained volunteers; and speech, physical, and occupational therapists, if needed.



What services are provided?

The interdisciplinary hospice team:

- Manages the patient's pain and other symptoms;
- Assists the patient and family members with the emotional, psychosocial, and spiritual aspects of dying;
- Provides medications and medical equipment;
- Instructs the family on how to care for the patient;
- Provides grief support and counseling;
- Makes short-term inpatient care available when pain or symptoms become too difficult to manage at home, or when the caregiver needs respite time;
- Delivers special services like speech language pathology and physical therapy when needed;
- Provides grief support and counseling to surviving family and friends.

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 and residential facilities. Hospice care may also be provided in freestanding hospice facilities and hospitals (see Levels of Care).



Introduction (continued)

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 Hospice 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 8 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 and are intended to maintain the terminally ill patient at home during a pain or symptom crisis.
- **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 that has sufficient 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 that has a registered nursing available 24 hours a day to provide direct patient care.



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 in that it is the only provider with Medicare Conditions of Participation (CoPs) requiring volunteers to provide at least 5% 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 that support patient care and clinical services (“clinical support”)
- Engaging in a variety of activities such as fundraising, outreach and education, and serving on a board of directors (“general support”).

Bereavement Services

Counseling or grief support for the patient and 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 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 at large, in addition to supporting patients and their families.

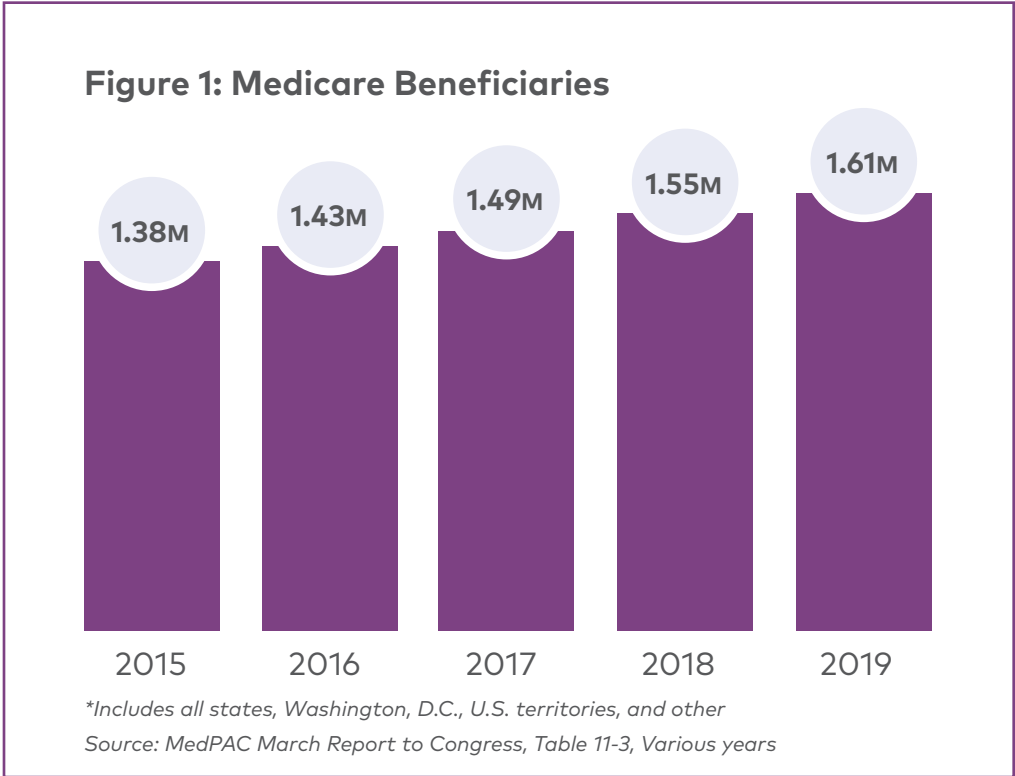
See page 24 for details on methodology and data sources, including cited references within the report.

Section 2: Who Receives Hospice Care

How many Medicare beneficiaries received hospice care in 2019?

As seen in Figure 1, 1.61 million Medicare beneficiaries who died were enrolled in hospice care for one day or more in 2019. This is a 3.9 percent increase from 2018. This includes patients who:

- Died while enrolled in hospice
- Were enrolled in hospice in 2018 and continued to receive care in 2019
- Left hospice care alive during 2019 (live discharges)

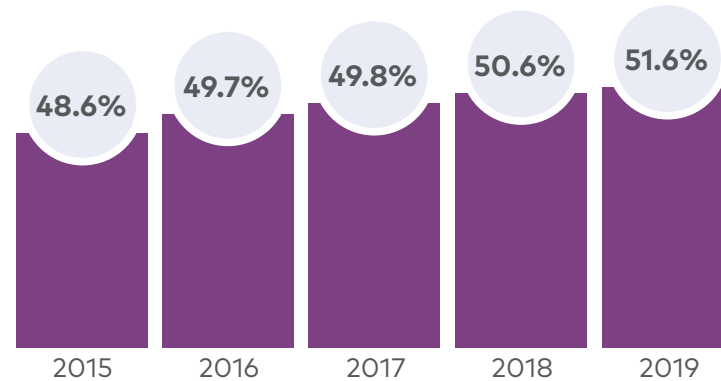


Who Receives Hospice Care (continued)

What proportion of Medicare decedents were served by hospice in 2019?

Of all Medicare decedents in 2019, as seen in Figure 2, 51.6 percent received one day or more of hospice care and were enrolled in hospice at the time of death.

Figure 2: Percent of Medicare Decedents Receiving 1 or more Days of Hospice Care in 2019

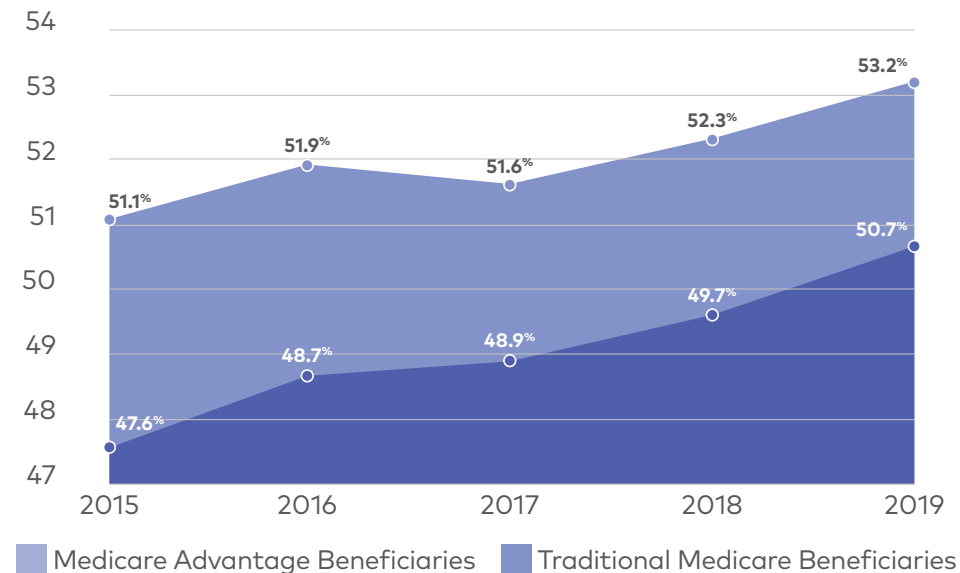


Source: MedPAC March 2021 Report to Congress, Table 11-2 and MedPAC March 2018 Report to Congress, Table 12-3

What % of Medicare Advantage Decedents Enrolled in Hospice between 2015 and 2019?

As demonstrated in Figure 3, utilization of the hospice benefit remains a bit higher among decedents enrolled in Medicare Advantage (MA) plans than among Traditional Medicare users, while the trendline for hospice usage continues to increase in both groups. MA decedents who utilized the hospice benefit rose from 51.1 percent in 2015 to 53.2 percent in 2019. During the same period, Traditional Medicare decedents utilizing the hospice benefit rose from 47.6 percent in 2015 to 50.7 percent in 2019.

Figure 3: Growth of Medicare Advantage Hospice Patients



Source: MedPAC March 2021 Report to Congress, Table 11-2 and MedPAC March 2018 Report to Congress, Table 12-3

Who Receives Hospice Care (continued)

What are the characteristics of Medicare beneficiaries who received hospice care in 2019?

Figure 4: Patient Gender

In 2019, among beneficiaries who identified as female and died in 2019, 56.2% used hospice and 43.8% did not. Among beneficiaries who identified as male and died in 2019, 46.7% used hospice and 53.3% did not.

Among Medicare decedents who identified as female

56.2%
used hospice



Among Medicare decedents who identified as male

46.7%
used hospice

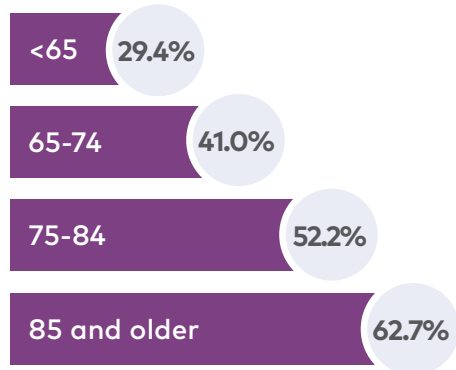


Source: MedPAC March 2021 Report to Congress, Table 11-2.

Patient Age

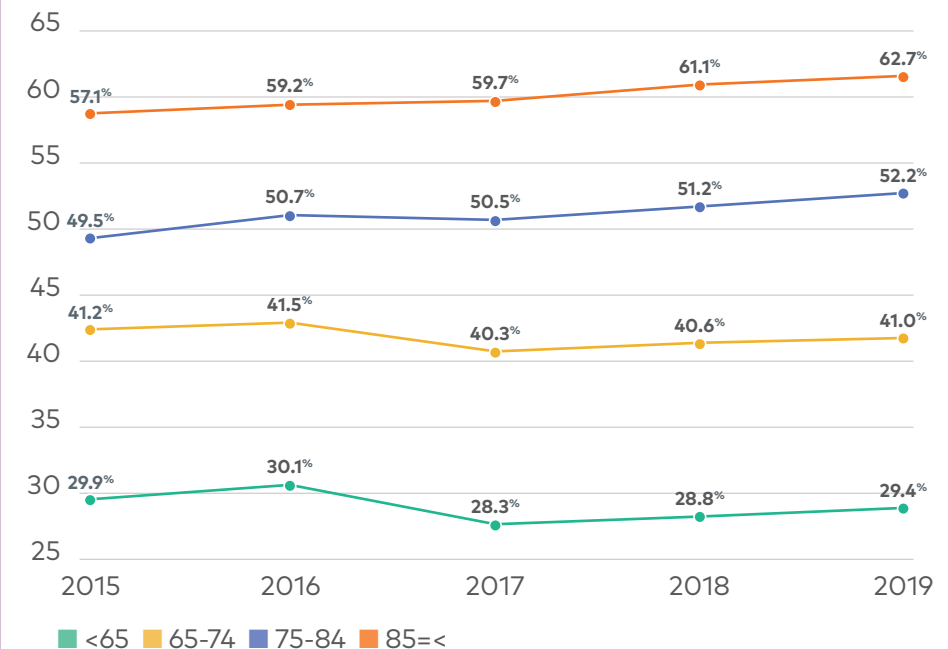
In 2019, as shown in Figure 5, nearly 63 percent of Medicare decedents age 85 years and older utilized the Medicare hospice benefit, while progressively smaller percentages of decedents in younger age groups received hospice care. Figure 6 shows that two of the four Medicare beneficiary age groups identified by MedPAC in its March 2021 Report to Congress saw increased usage of the Medicare hospice benefit over the five year period from 2015 to 2019.

Figure 5: % of Patients by Age group for 2019



Source: MedPAC March 2021 Report to Congress, Table 11-2.

Figure 6: % Change over 5 Years



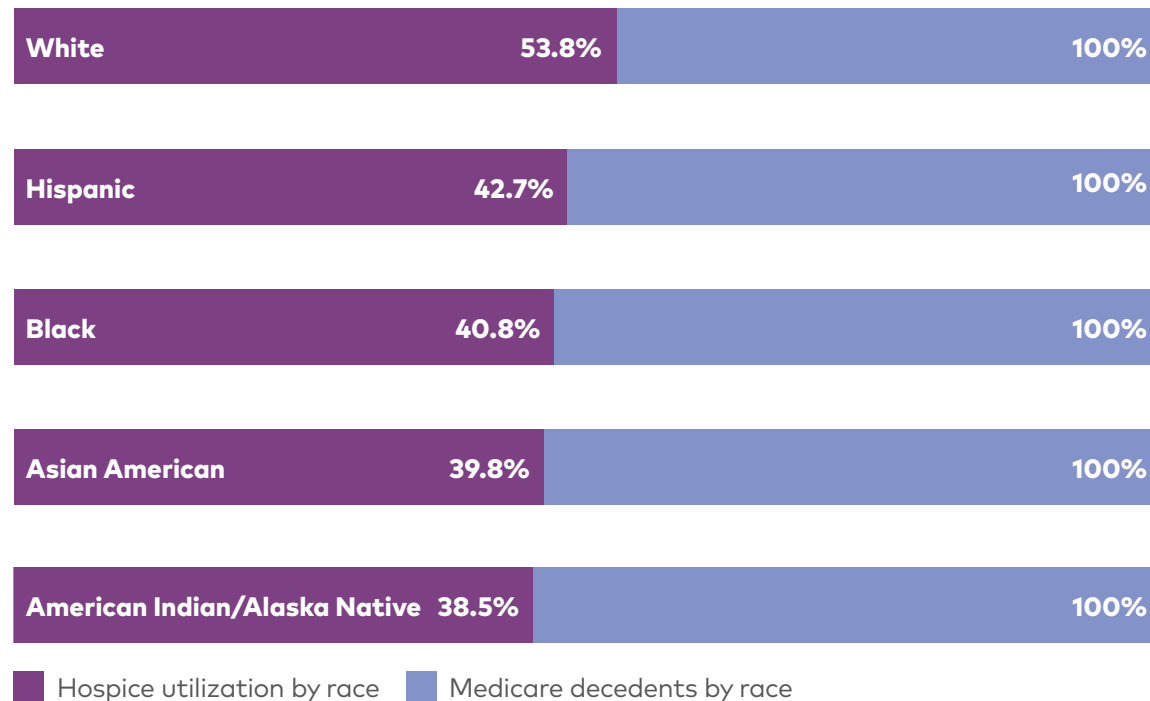
Who Receives Hospice Care (continued)

What are the characteristics of Medicare beneficiaries who received hospice care in 2019?

Patient Race

In 2019, almost 54 percent of White Medicare decedent beneficiaries used the Medicare hospice benefit (53.8 percent). Nearly 43 percent (42.7) of Hispanic Medicare beneficiaries and almost 41 percent (40.8) of Black Medicare beneficiaries enrolled in hospice in 2019. More than 38 percent of Asian American and American Indian/Alaska Native Medicare decedents used hospice in 2019.

Figure 7: % of Medicare decedents by race who used hospice



Source: MedPAC March 2021 Report to Congress, Table 11-2

Note: In previous years, the NHPCO Facts and Figures has presented data on the share of Medicare beneficiaries who used hospice by race. In an effort to focus on equity, we are now presenting data from the 2019 MedPAC March report to Congress, Table 11-2, focused on the percentage of Medicare decedents by race who used hospice.

Who Receives Hospice Care (continued)

What are the characteristics of Medicare beneficiaries who received hospice care in 2019?

Principal Diagnosis

The principal hospice diagnosis is the diagnosis that has been determined to be the most contributory to the patient's terminal prognosis. Specific diagnoses have been collapsed into major disease groupings in Figures 8 and 9 to the right. 2019 showed that more Medicare hospice patients had a principal diagnosis of Alzheimer's/Dementia/Parkinson's than any other disease.

Principal diagnosis categories of Stroke, Respiratory, and Circulatory/Heart have grown the most since 2014.

Figure 8: Percentage of Medicare Decedents Using Hospice by Top 15 Principal Diagnoses

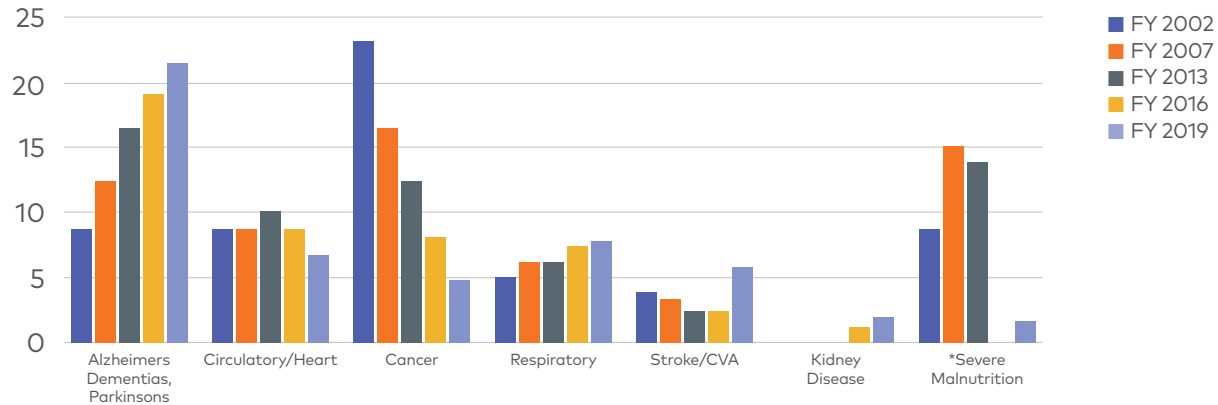
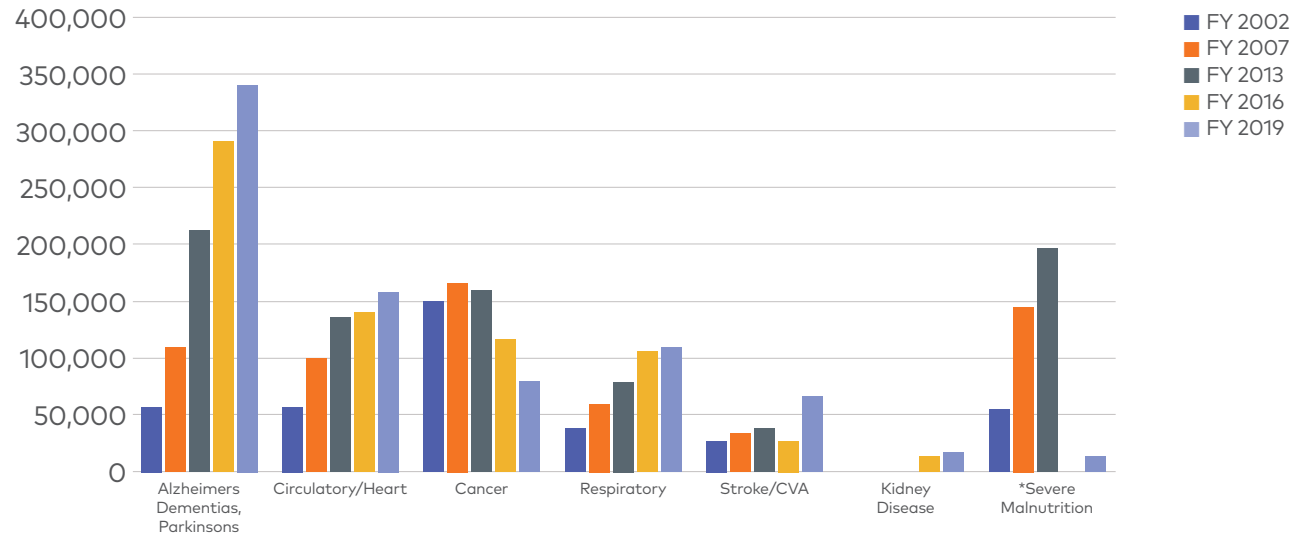


Figure 9: Number of Medicare Decedents Using Hospice by Top 15 Diagnoses



* In 2002, 2007 and 2013, severe malnutrition includes debility unspecified and adult failure to thrive. Those diagnoses were disallowed and no longer used in later years.

Source: CMS-1675-P, FY 2018 Hospice Wage Index and Payment Rate Update and Hospice Quality Reporting Requirements and CMS-1754-P Medicare Program; FY 2022 Hospice Wage Index and Payment Rate Update, Hospice Conditions of Participation Updates, Hospice and Home Health Quality Reporting Program Requirements

Section 3: How Much Care Is Received?

Length of Stay

The average Length of Stay (LOS) for Medicare patients enrolled in hospice in 2019 was 92.6 days. The median length of stay (MLOS) was 18 days.

Table 1: Average and Median Length of Stay

Year	Total Days (in millions)	Average Length of Stay	Median Length of Stay	Number of Patients (in millions)
2015	95.9	86.7	17 days	1.38
2016	101.2	87.8	18 days	1.42
2017	106.3	89.3	18 days	1.49
2018	113.5	90.3	18 days	1.55
2019	121.8	92.6	18 days	1.61

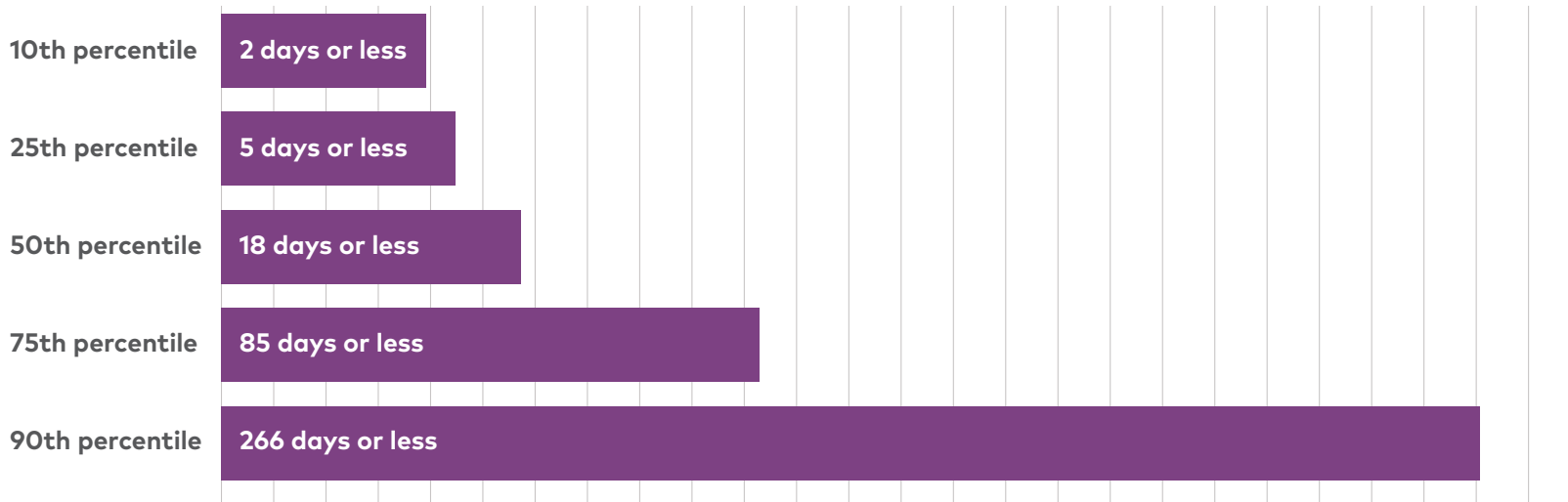
Source: MedPAC March 2021 Report to Congress, Table 11-3 and the MedPAC March 2018 Report to Congress, Table 12-4

How Much Care Is Received (continued)

Days of Care by Length of Stay in 2019

- 10% of patients were enrolled in hospice for 2 days or less.
- 25% of patients were enrolled in hospice for 5 days or less.
- 50% of patients were enrolled for 18 days or less.
- 75% of patients were enrolled for 85 days or less.
- At the 90th percentile, 10% of patients were enrolled for more than 266 days.

Figure 10: Days of Care



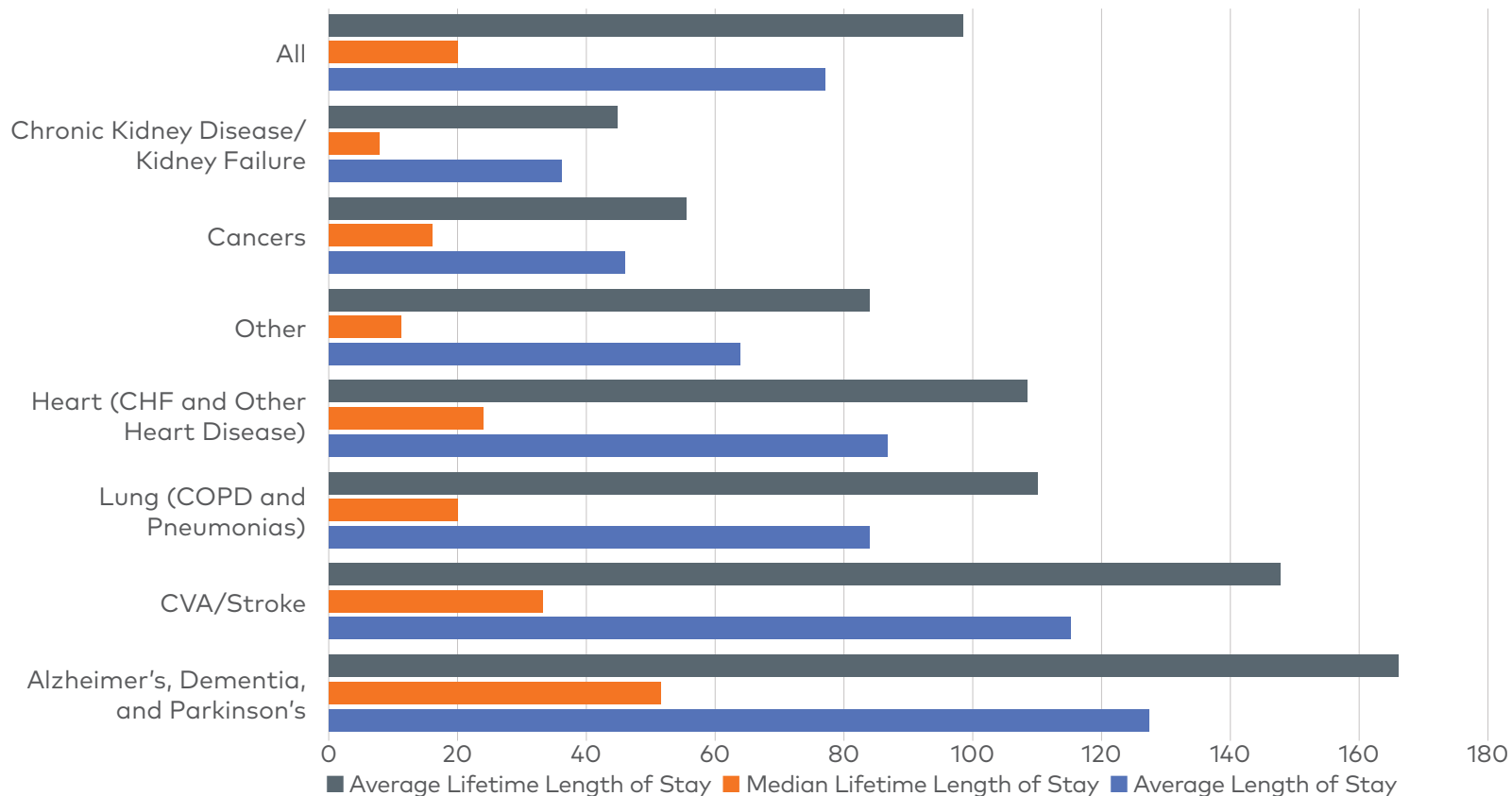
Source: MedPAC March 2021 Report to Congress, Figure 11-1.

How Much Care Is Received? (continued)

Days of Care

Figure 11 depicts the average lifetime, average and median lifetime length of stay for major hospice disease categories. Average and median lifetime lengths of stay are defined by CMS as “the sum of all days of hospice care across all hospice elections.” In 2019, as seen in Figure 11, patients with Alzheimer’s, dementias and Parkinson’s used the Medicare Hospice benefit for the greatest average, lifetime average, and median length of stay in days. This contrasts with chronic kidney disease/kidney failure and cancer patients, who utilized the Medicare hospice benefit for a much lower average and median number of days in 2019.

Figure 11: Days of Care by Principal Diagnosis for 2019



Source: FY 2022 Hospice Wage Index and Quality Reporting Proposed Rule, Table 6

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 his or her lifetime.

How Much Care Is Received? (continued)

Live Discharges and Transfers

In 2019, out of all Medicare hospice discharges, 17.4 percent of all Medicare beneficiaries using hospice were discharged alive, with patient-initiated and hospice-initiated discharges being about equal.

Table 2: Discharge by Type and Reported Reason, 2017-2019

Reason for Discharge	2017	2018	2019
All discharges	16.7%	17.0%	17.4%
Patient-Initiated Live Discharges			
Revocation	6.4	6.6	6.5
Transferred to another hospice	2.1	2.2	2.3
Hospice-Initiated Live Discharges			
No longer terminally ill	6.5	6.3	6.5
Moved out of service area	1.4	1.6	1.7
Discharged for cause	0.3	0.3	0.3

**Calculations are based on total number of discharges which includes patients who were discharged more than one time in 2019.*

Source: MedPAC March 2021 Report to Congress, Table 11-11.

How Much Care Is Received? (continued)

Location of Care

In 2019, most of days of care were provided at a private residence followed by nursing facilities and assisted living facilities.

Average days by location of care as shown in Figure 12 were 95 days at a private residence, 109 days in nursing facilities, and 161 days in assisted living facilities. Median length of stay by location of care, shown in Figure 13, were 27 days at a private residence, 22 days in nursing facilities and 56 days in assisted living facilities.

Table 3: Location of Care by Average and Median Days of Care for 2019

	Average	Median
Private Residence	95	27
Nursing Facility	109	22
Assisted Living Facility	161	56

Figure 12: Average Days by Location of Care

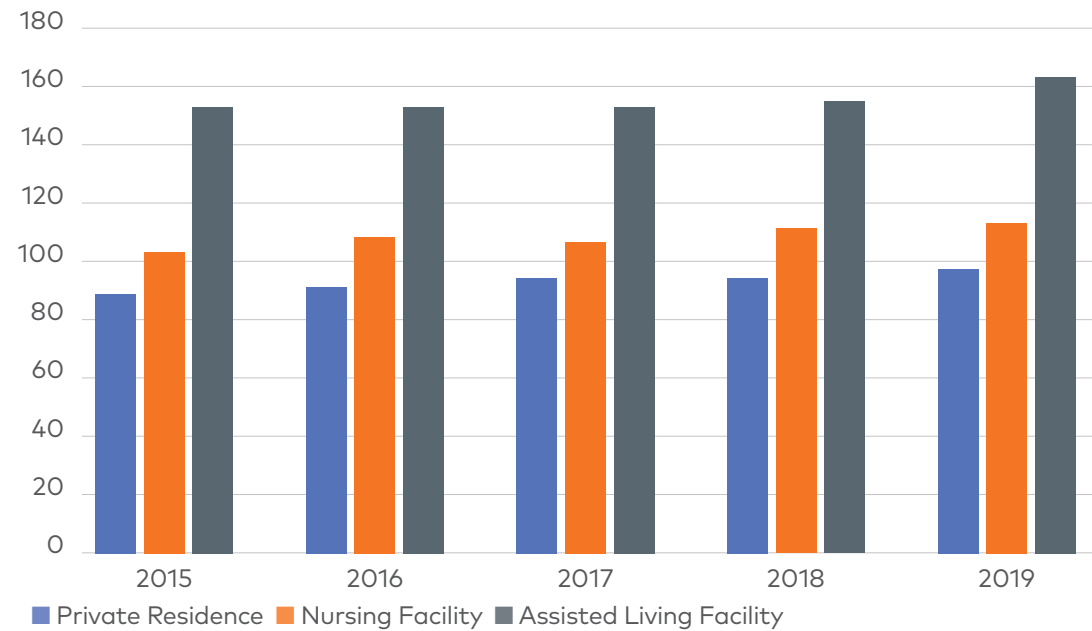
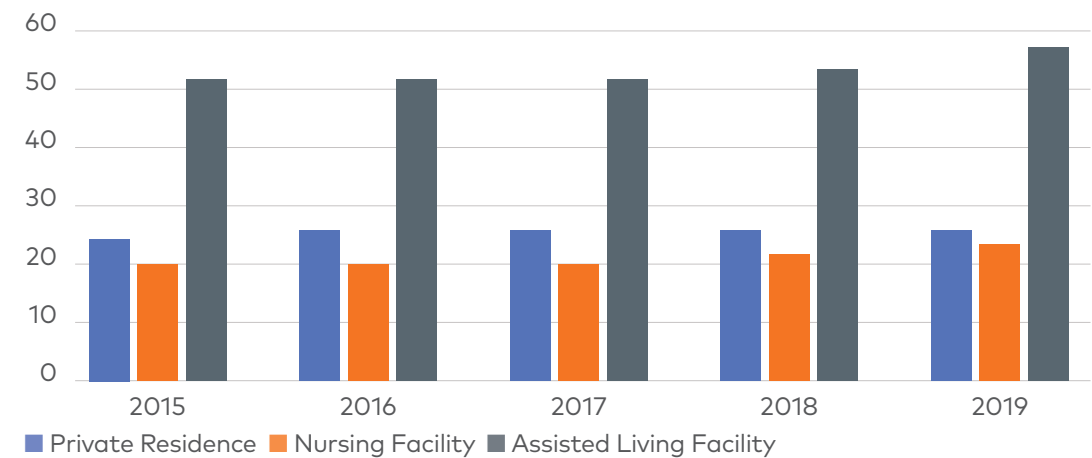


Figure 13: Median Days by Location of Care

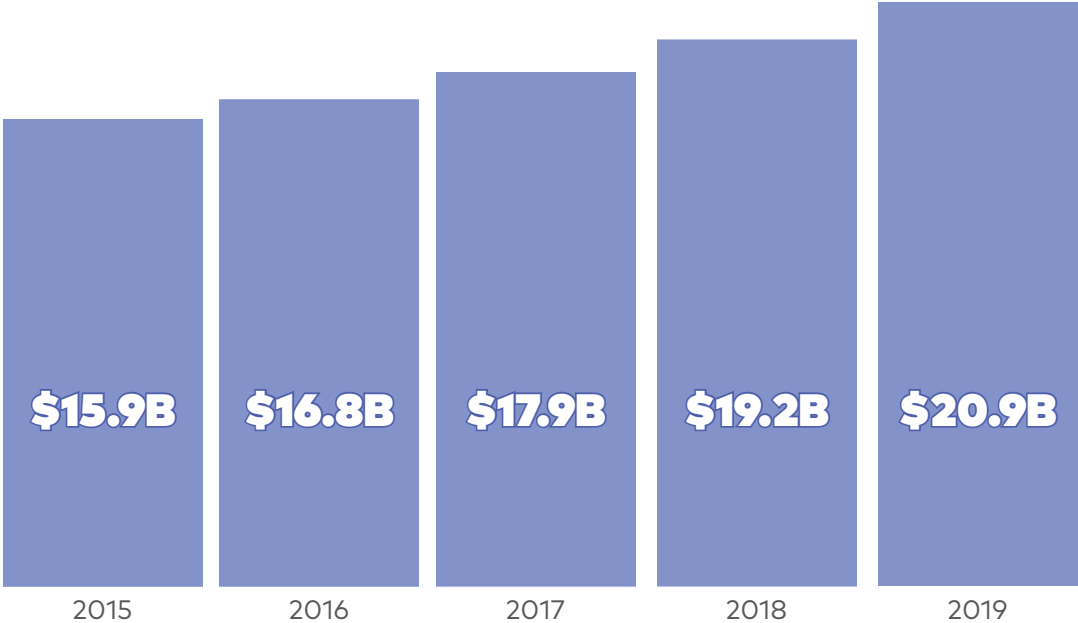


Source: MedPAC March 2021 Report to Congress, Table 11-4

Section 4: How Does Medicare Pay for Hospice?

Medicare paid hospice providers a total of \$20.9 billion dollars for care provided in 2019, representing an increase of 8.5% over the previous year.

Figure 14: Medicare Spending



Source: MedPAC March 2021 Report to Congress, Table 11-3 and MedPAC March 2018 Report to Congress, Table 12-4.

How Does Medicare Pay for Hospice? (continued)

Spending by Level of Care

In 2019, the vast majority of Medicare spending for hospice care was for care at the routine home care (RHC) level.

Table 4: Percent of Days by Spending

Level of Care (LOC)	2019
Routine Home Care (RHC)	93.8%
General Inpatient Care (GIP)	4.9%
Inpatient Respite Care (IRC)	0.3%
Continuous Home Care (CHC)	0.9%

Source: FY 22 Hospice Wage Index, Proposed Rule, Table 5

Table 5: Percent of Days by Level of Care

Level of Care (LOC)	2015	2016	2017	2018	2019
Routine Home Care (RHC)	97.9%	98.0%	98.0%	98.2%	98.3%
Continuous Home Care (CHC)	0.3%	0.3%	0.2%	0.2%	0.2%
Inpatient Respite Care (IRC)	0.3%	0.3%	0.3%	0.3%	0.3%
General Inpatient Care (GIP)	1.6%	1.6%	1.3%	1.2%	1.2%

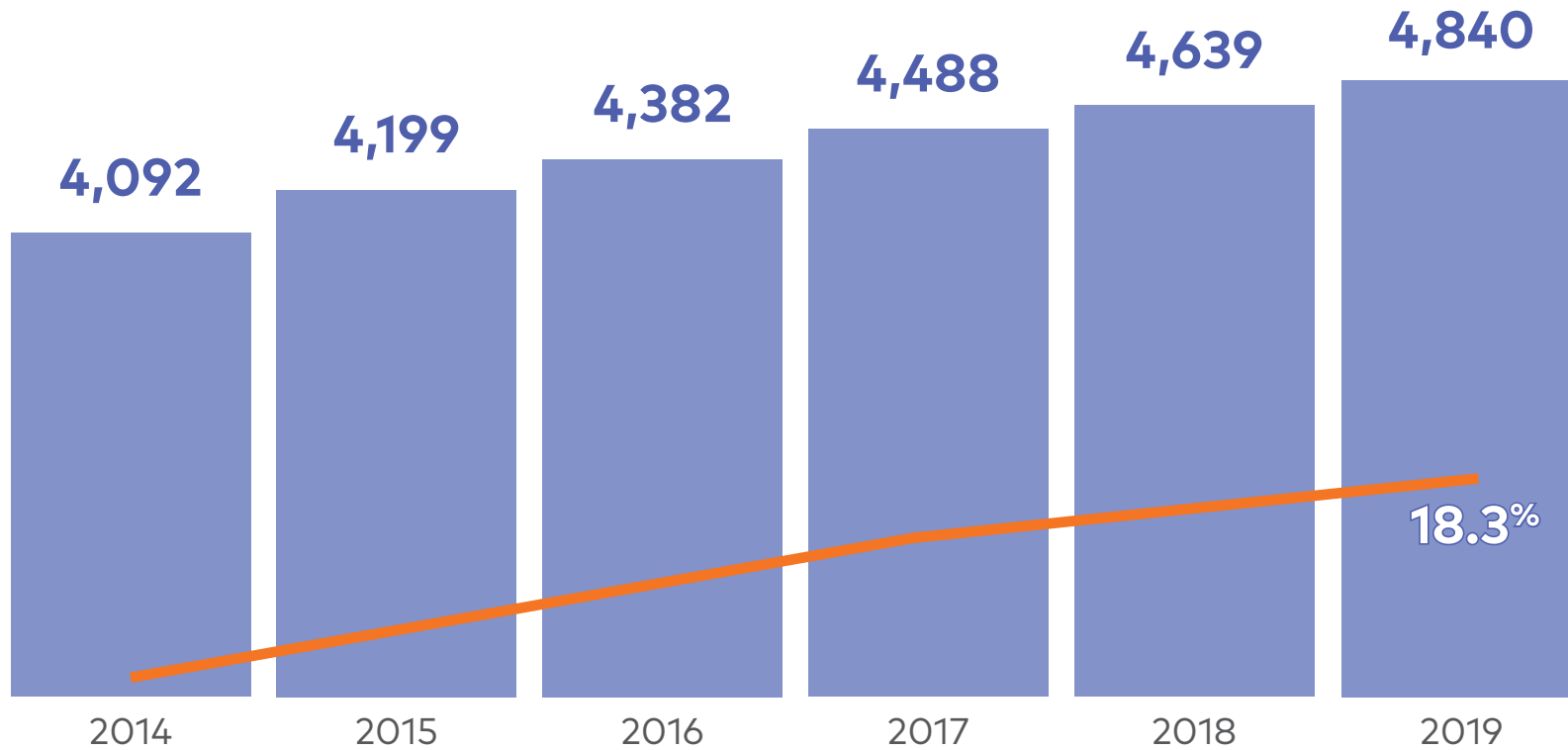
Source: MedPAC March Report to Congress, various years and FY 2022 Hospice Wage Index and Quality Reporting Proposed Rule, April 2021

Section 5: Who Provides Care?

How many hospices were in operation in 2019?

Over the course of 2019, there were 4,840 Medicare certified hospices in operation based on claims data. This represents an increase of 18.3% since 2014.

Figure 15: Number of Operating Hospices



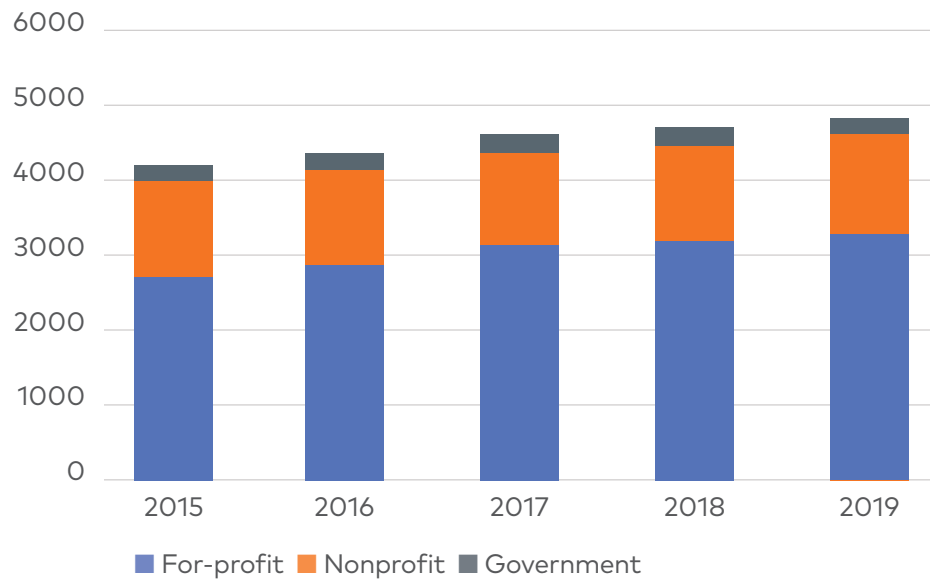
MedPAC March 2021 Report to Congress, Table 11-1. and MedPAC March 2018 Report to Congress, Table 12-3.

Who Provides Care? (continued)

Tax Status

As shown in Figure 19, the growth in hospice ownership is being driven by the growth in for-profit ownership. As reported by MedPAC in the March 2021 Report to Congress, between 2018 and 2019, the number of for-profit hospices increased by 6.3 percent, while the number of nonprofit hospices increased by 0.2 percent, and government owned hospices declined by 5.7 percent. As of 2019, about 71 percent of hospices were for profit, 26 percent were nonprofit, and 3 percent were government owned.

Figure 16: Providers by Type



Source: MedPAC March Report to Congress, Various Years

Data Sources

The data sources primarily used for this report are from the Medicare Payment Advisory Commission (MedPAC) March Report to Congress (various years) and the FY 2022 Hospice Wage Index and Quality Reporting Proposed Rule, published in the Federal Register on April 14, 2021. See cited sources through out the report for each table and figure.

For data references provided by MedPAC, the March Report to Congress from various years are used. They can be found at www.medpac.gov.

For data references provided by the Centers for Medicare and Medicaid Services (CMS), the FY 2022 Hospice Wage Index and Quality Reporting Proposed Rule, (CMS-1754-P) was published in the Federal Register at www.govinfo.gov/content/pkg/FR-2021-04-14/pdf/2021-07344.pdf on April 14, 2021.

Questions May Be Directed To:

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Suggested Citation:

2021 Edition: Hospice Facts and Figures. Alexandria, VA:

National Hospice and Palliative Care Organization.

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OCTOBER 2021