

Death and Dying in Hampton Roads



DEATH AND DYING IN HAMPTON ROADS

"Life Is Pleasant. Death Is Peaceful. It's the Transition That's Troublesome."

Isaac Asimov

First introduced in the United States in 1963, hospice care is the specialized treatment that provides support and comfort to patients who are terminally ill with a general life expectancy of six months or less. According to the National Center for Health Statistics, more than 1.5 million patients received hospice services in the US in 2017.¹ These individuals suffered from life-limiting illnesses such as end-stage heart disease; cancer; neurodegenerative diseases, such as Parkinson's disease; lung or kidney disease; or Alzheimer's and other dementias.

Hospice care was added as a permanent Medicare benefit in 1985 and is designed to help patients live as comfortably as possible during their remaining time, with a focus on managing symptoms, pain relief, and end-of-life (EOL) support. This care is often provided at home but can also be delivered in an outpatient clinic or inpatient setting. In 2020, Medicare spending on hospice care reached \$22.4 billion.² As the population ages in Hampton Roads, Virginia, and the United States, hospice care will only increase in importance over the coming decade.

Quality care is essential for patients with serious and terminal illnesses as it improves patient outcomes, provides comprehensive and specialized care, manages pain and symptoms, offers emotional support, ensures dignified end-of-life care, promotes coordination and continuity of care, and embraces patient and family-centered approaches. A recent interview with a family member of a hospice patient who recently passed away from colon cancer in Norfolk provided insight on quality care and understanding the system. "When my Mom was diagnosed and began receiving hospice care visits in my home, I had no idea where the person was coming from, a profit/nonprofit, I didn't even know there was a distinction. I thought it was run by a church or other nonprofit. However, all hospices are not the same, care can come from for-profits, part of a national chain. Also, within my family, my brother near

Franklin wanted to help me with respite care if we could find home hospice care in his rural location. However, it was very difficult and that even limited our family choices. Before my mother's illness, I knew extraordinarily little about who provided hospice care in Norfolk or other locations in the area. Over time, I learned what services were available and that my Mom did have a choice in providers, but it was slow and difficult."

In this chapter, we will take a close look at serious disease and hospice care in the United States and Virginia. We examine the demand for hospice care by Medicare beneficiaries and the changing nature of hospice care suppliers as now more than two-thirds of hospices nationwide operate as for-profit entities. We scan our region for care services for the seriously ill and ultimately ask the question: what is the state of end-of-life care in Hampton Roads?

¹ Post-acute and Long-term Care Providers and Services Users in the United States, 2017–2018 Analytical and Epidemiological Studies, National Center for Health Statistics, Series 3, Number 47, May 2022.

² Value of Hospice in Medicare, NORC at the University of Chicago, March 2023, https://www.nhpco.org/wp-content/uploads/Value_Hospice_in_Medicare.pdf

A Primer on Hospice Care

If we wish to focus on hospice and end-of-life (EOL) care, then we need to sharpen our awareness of terminology. For those who are not acquainted with this topic or have not experienced the death of a loved one in this way, language can be a challenge surrounding this often difficult to discuss subject. To avoid confusion, we define commonly used terms in this chapter and provide a discussion of each term. To start, there are different types of care for individuals with illnesses: curative, palliative, and hospice.

Curative care refers to treatments provided to an individual at any age or illness stage with the primary goal of curing their illness or condition. A hospital stay for an appendectomy is an example of curative care. Curative care can range from relatively mild conditions to quite complex medical conditions that require intensive medical intervention and extended stays in medical facilities.

Palliative care is care designed to soothe the symptoms of someone suffering from a serious illness and is typically part of care for people with cancer. For any age or stage of illness, this type of care may also be referred to as supportive care. Palliative care can be administered at the same time as curative care and may even assist in illness recovery, if recovery is possible.

Hospice care is a specific type of palliative care for individuals who have been identified to have six months or less of life due to severe illness, life threatening condition and/or other medical factors. When a patient chooses hospice care, they waive their rights to Medicare coverage of disease-focused curative treatments for their terminal illness. However, treatments and services to reduce pain or symptom severity and manage terminal illness and related conditions are included in the hospice benefit. This prognosis can only be determined by a physician, and the hospice benefit does not expire. The initial hospice benefit period starts when the patient signs up for hospice and the period lasts for 90 days, if needed. After the first 90 days, the patient will be approved for an additional 90 days. Treatment during hospice care refers to alleviating symptoms and providing comfort when possible as there is no curative treatment being administered.

A patient always has control over the type of care received. For example, if a medical condition or illness improves or the patient prefers to leave hospice care, they are free to do so. Medical professionals would agree that when six months or less is identified for hospice qualification, this determination is based upon the expected course of the patient's medical condition. However, no two patients are ever the same, and disease progression may be faster or slower than the six-month time frame. After six months, a patient may be recertified after an in-person visit by a qualified health professional when the patient's condition remains life-limiting.

Patients and their loved ones often want and need information and support surrounding the seriousness or finality of a diagnosed illness. However, medical professionals are only in the position to estimate this information based on what they know about the patient's medical history and the diagnosed illness. Over- or underestimating life span is fraught for many reasons. Supportive care to deal with the emotional challenges associated with an end-of-life diagnosis and care are available through hospice including counseling and respite care. Respite care provides short-term relief for the primary caregiver of an ill patient and offers the caregiver assistance and rest from providing constant care for a temporary period of time.

Lastly, after the patient's death, bereavement services are designed to help individuals navigate the difficult emotions that come with losing a loved one. The Medicare Hospice Benefit provides bereavement services for at least one year. Many religious organizations also provide bereavement services, for example, the Grief Share program is commonplace throughout churches in Hampton Roads.

Hospice Care and Health in the United States

Inspired by St. Christopher's Hospice in London in 1967, Florence Wald founded the first "official" hospice in the United States. Established in 1973 in Branford, Connecticut, the Connecticut Hospice eventually became the model for hospice care across the nation. Dr. Elisabeth Kübler-Ross' groundbreaking book, *On Death and Dying*, which described five stages of grief, propelled the relatively new discussion of end-of-life care for the terminally ill to the American lexicon over 50 years ago. Evidence suggests that the prevalence of certain diseases has increased over time and expanded social awareness of serious illness and end-of-life conditions; this is vital to promoting better health outcomes and creating a supportive environment for those impacted. The National Institute on Aging defines serious illness as "a disease or condition with a high risk of death." Awareness initiatives play a crucial role in improving public health, advancing research, and enhancing the quality of life for individuals and communities. Consider the importance of the discussion of serious diseases such as cancer in the United States and Virginia.

Heart disease and cancer are the leading causes of death in the nation. In 2020, over 1.6 million new cases of cancer were reported, and over 602,000 people died of cancer. One of every five deaths in the United States is due to cancer. Cancer is the leading cause of death in midlife and is poised to become the leading cause of death overall as the number of people diagnosed with and dying from cancer continues to increase.³ By 2050, the number of colorectal cancers is predicted to exceed the total number of lung and bronchus cancers.⁴ It is important to note that while the incidence of certain cancers has increased, advancements in medical treatments and interventions have also improved survival rates for many types of cancer. Early detection, better treatment options, and increased awareness have helped in managing and treating cancer more effectively. Nonetheless, especially as our population ages, it stands to reason that age is a significant risk factor for many types of cancer, and as life expectancy has increased, more individuals are living long

enough to develop cancer. Individuals with a Stage 4 diagnosis, as defined by the National Cancer Institute as cancer having spread to "distant parts of the body," will be offered support care as curative care becomes limited.

The Bureau of Economic Analysis (BEA) Health Care account estimates health care spending by medical disease. Graph 1 illustrates the rise of disease costs in the United States from 2001 to 2020 with cancer remaining relatively persistent over that period. Of special note in Graph 1 is the impact of the COVID-19 pandemic's first year spending on infectious diseases, jumping from \$83.3 billion in 2019 to more than \$222 billion in 2020.

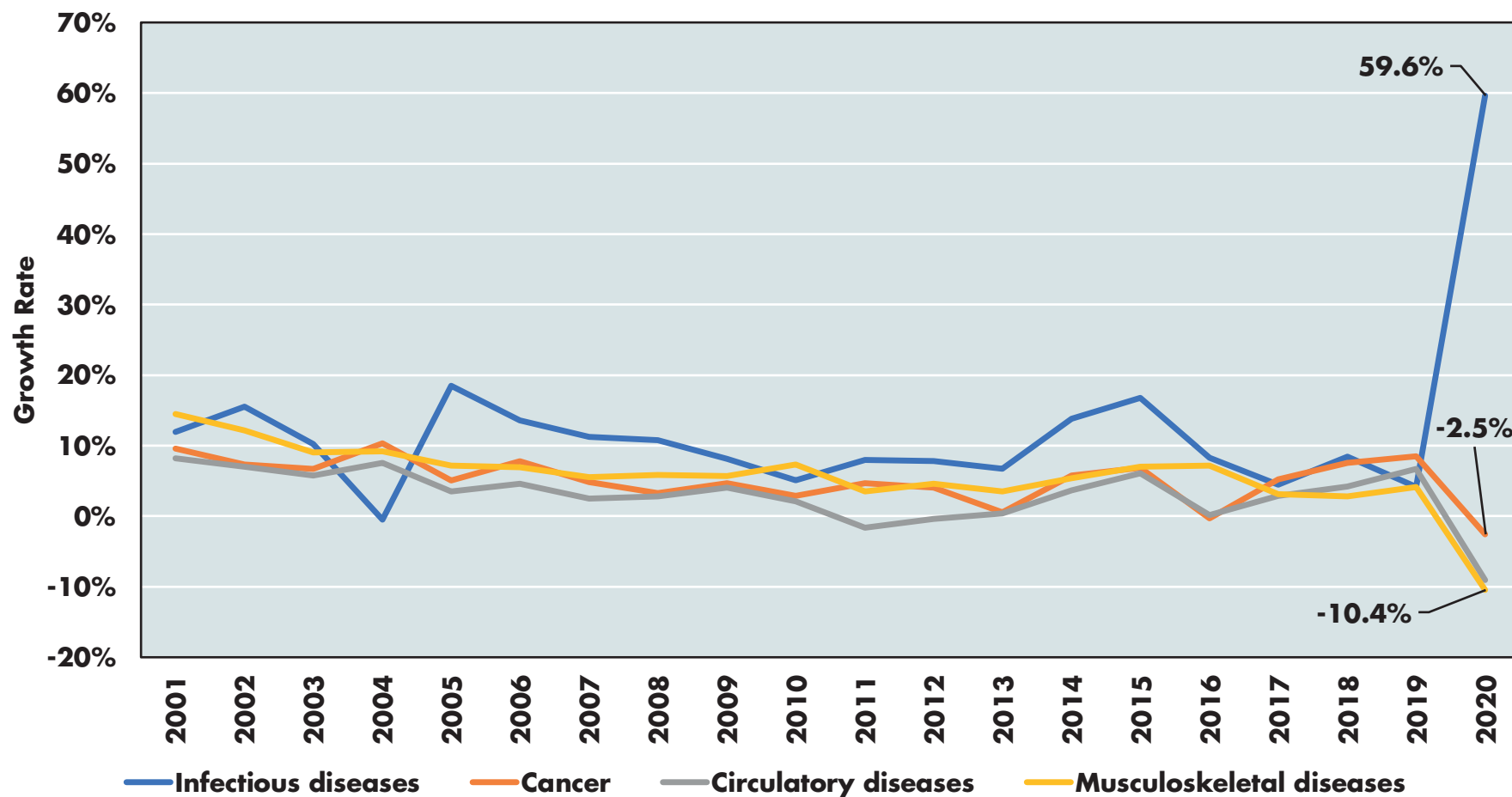
The Centers for Disease Control (CDC) officials have cautioned interpreting 2020 hospice data because the pandemic disordered health services. Closures and the suspension of health services due to social distancing led to delays and/or reductions in cancer screening, diagnosis, and reporting of disease. It is suspected that any decline in new cancer cases in 2020 may be due to the disruption of COVID-19 on routine health services. In addition, during the midst of the pandemic, deaths of the terminally ill were complicated by the introduction of COVID-19 fatalities. The long-lasting impacts of COVID-19 on data gathering in the United States include disruptions to data collection, changes in data collection methods, increased focus on health data, disparities and equity considerations, and reliance on real-time data. These effects will likely shape health care going forward in the post-pandemic era.

Table 1 reports the top 10 leading causes of death in the U.S. and Virginia in 2021 as reported by the National Vital Statistics System (NVSS) and CDC WONDER. Not surprisingly, the top-five leading causes of death for the nation and the Commonwealth are the same. We note (again) that these statistics are impacted by the COVID-19 pandemic, with COVID-19 deaths ranking third nationally and in Virginia in 2021.

³ U.S. Cancer Statistics Working Group. 2023. <https://www.cdc.gov/cancer/U.S.cs/dataviz/index.htm>

⁴ Weir HK, Thompson TD, Stewart SL, White MC. Cancer Incidence Projections in the United States Between 2015 and 2050. *Prev Chronic Dis.* 2021 Jun 10;18:E59. doi: 10.5888/pcd18.210006. PMID: 34114543; PMCID: PMC8220959

GRAPH 1
ANNUAL EXPENDITURE GROWTH BY DISEASE
UNITED STATES, 2001-2020



Source: US Bureau of Economic Analysis, <https://www.bea.gov/news/blog/2023-02-10/new-health-care-statistics-first-year-covid-19-pandemic>

TABLE 1 TEN LEADING CAUSES OF DEATH, UNITED STATES, 2021		
Rank	United States	Virginia
1	Heart Disease	Heart Disease
2	Cancer	Cancer
3	COVID-19	COVID-19
4	Accidents	Accidents
5	Stroke	Stroke
6	Chronic Lower Respiratory Diseases	Chronic Lower Respiratory Diseases
7	Alzheimer's Disease	Diabetes
8	Diabetes	Alzheimer's Disease
9	Chronic Liver Disease/ Cirrhosis	Kidney Disease
10	Kidney Disease	Suicide

Source: National Center for Health Statistics (2023). A total of 3,464,231 resident deaths were registered in the United States in 2021. The 10 leading causes of death accounted for 74.5% of all U.S. deaths in 2021. Causes of death are ranked according to number of deaths. Virginia: National Center for Health Statistics (2023). Death data, including leading causes of death, come from the NVSS and CDC WONDER, and rankings are based on 2021 age-adjusted death rates.

Table 2 reports the number of cancer deaths and death rate in the Commonwealth for selected years, 2005 to 2021. The number of deaths from cancer in Virginia has risen since 2005 but so has the population of the state. If we examine the death rate from cancer, which is equal to the number of cancer deaths relative to the population, then the story is different. In 2005, the death rate from cancer in the Commonwealth was 190.0 per 100,000 residents. In 2019, the cancer death rate had fallen to 144.9 per 100,000 residents. While the death rate increased in 2021, it was still almost 21% below the level observed in 2005.

TABLE 2 CANCER MORTALITY, VIRGINIA, SELECTED YEARS, 2005-2021		
Year	Death Rates	Number Of Deaths
2005	190.0	13,877
2014	161.5	14,749
2015	159.5	14,947
2016	156.1	15,027
2017	152.6	15,064
2018	149.3	15,148
2019	144.9	15,045
2020	146.6	15,499
2021	150.5	15,724

Sources: CDC WONDER and the Dragas Center for Economic Analysis and Policy, Old Dominion University. The number of deaths per 100,000 total Virginia population.

Life-threatening diseases and conditions in the United States and Virginia such as cancer, respiratory diseases, and neurodegenerative disorders, contribute to a demand for end-of-life care services. One important factor in meeting the potential increase in demand for hospice care is that policymakers and communities should work together to ensure adequate resources, funding, and access to hospice services. This includes expanding hospice programs, increasing awareness and education about end-of-life care options, and supporting initiatives that promote compassionate and high-quality care for individuals with life-limiting illnesses. One such monumental change, the inclusion of hospice services as a Medicare benefit, drastically changed end-of-life care in the United States over 40 years ago.

Hospice Care and the Medicare Benefit

In 1982, the Medicare Hospice Benefit was added to the Social Security Act, which allowed hospice care to be covered by Medicare. This addition was a significant development in United States health care for several reasons. By including a hospice benefit, Medicare expanded access to specialized end-of-life care for millions of eligible beneficiaries. This ensured that individuals nearing the end-of-life could receive the necessary support and services without facing financial hardship. Graphs 2 and 3 report Medicare beneficiary participation and Hospice spending because of this landmark policy change. **In 2020, there were more than 1.7 million Medicare patients receiving hospice care.**

According to the National Hospice and Palliative Care Organization (NHPCO), Virginia had a 46.2% utilization of hospice with Medicare decedents receiving one or more days of hospice care and being enrolled in hospice at the time of death in 2020 (Table 3). In the U.S., Utah is the state with the highest utilization at over 60%, and New York had the lowest use with 24%. The average length of stay in 2020 for the 1.72 million Medicare patients in Hospice care was 97 days. The NHPCO reports that it is the largest increase in the previous five years.⁵ The number of beneficiaries using hospice services at the end-of-life grew 9% in 2020. A principal diagnosis of cancer was the leading diagnosis among Medicare hospice patients, followed by circulatory/heart disease and dementia. Table 4 reports total number of traditional Medicare hospice users in the U.S. and Virginia in 2020.

Prior to the addition of the Medicare hospice benefit, individuals and their families often had to bear these expenses themselves or rely on limited insurance coverage. Another gain of adding a hospice benefit to Medicare was that individuals now received the ability to choose the type and location of care aligning with their personal preferences and values. The inclusion of a hospice benefit in Medicare demonstrated a recognition of the unique needs

and challenges faced by individuals nearing the end-of-life. It highlighted the importance of providing specialized care, support, and resources. This governmental acknowledgment helped foster a broader societal understanding of end-of-life care and the significance of compassionate and comprehensive services for patients and their families. Adding a hospice benefit to Medicare was a landmark development because it expanded access to specialized end-of-life care, provided financial relief, empowered patient choice, improved care coordination, emphasized palliative care, and recognized the specific needs of individuals nearing the end-of-life.⁶

The Virginia Association for Hospices and Palliative Care states Medicare coverage includes doctor and nursing care, hospice aides, social work services, counseling services, supplies, physical, occupational and speech therapy, pain management, respite care, and grief support. Hospice care is available in a variety of settings, including in the home, hospice facilities, and hospitals. In the Medicare Payment Advisory Commission presentation to Congress in 2023, the independent congressional agency reported that the number of hospice providers increased by 6% in 2021 because of for-profit hospices, following a decades-long trend of increases in for-profit providers.⁷ As of 2020, over 70% of providers were for-profit. Graph 4 shows the total number of hospice providers in the United States. In 2020, there were over 5,000 Medicaid-certified hospices operating in the U.S.

Graph 5 reports data by the NHPCO on the total number of Medicare decedents using Hospice in the U.S. in 2019 and 2020 by principal diagnosis. In 2020, there were 374,992 deaths in U.S. hospices due to Alzheimers, dementias, and Parkinsons. The impact of the global pandemic is evident as over 31,000 hospice users died from COVID-19, which was non-existent in the 2019 data. In 2020, Medicare decedents in hospice care at the time of their death were majority female and white. Other racial groups were comparable in hospice usage: 36% Asian American, 35.5% Black, 33.5% American Indian/Alaska Native and 33.3% Hispanic.

⁵ Hospice Care in America - NHPCO's Facts and Figures 2022 <https://www.nhpco.org/wp-content/uploads/NHPCO-Facts-Figures-2022.pdf>

⁶ For more key facts on the history of Hospice including the AIDS crisis and the Patient Care Act, visit <https://www.nhpco.org/hospice-care-overview/history-of-hospice/>

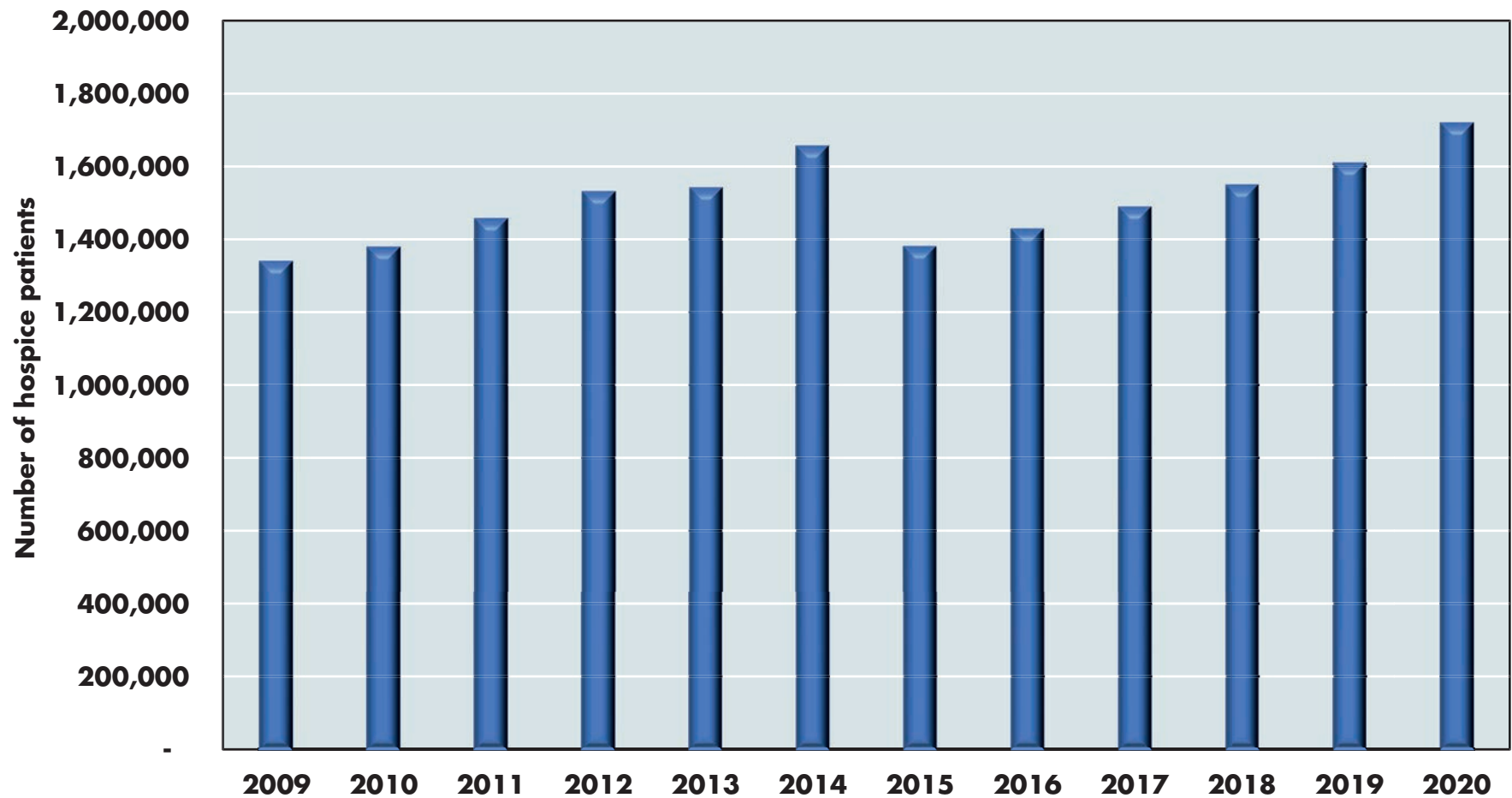
⁷ Medicare Payment Advisory Commission report https://www.medpac.gov/wp-content/uploads/2023/03/Mar23_MedPAC_Report_To_Congress_SEC.pdf

Graph 6 presents the share of Medicare recipients who utilized hospice services in 2021. The largest age category for this population is 59% of the oldest adults over the age of 85. While many may think hospice is only for the elderly population, the data suggest otherwise. More than 1 in 4 hospice patients in 2020 were under the age of 65.

TABLE 3		
USE OF HOSPICE SERVICES IN TRADITIONAL MEDICARE, UNITED STATES AND VIRGINIA, 2020		
	Total Part A Enrollees	Total Persons with Utilization
United States	61,211,371	1,717,193
Virginia	1,540,473	39,930
Sources: https://www.kff.org/medicare , The Henry J. Kaiser Family Foundation, Centers for Medicare & Medicaid Services, Office of Enterprise Data and Analytics, CMS Chronic Conditions Data Warehouse. Note: The total Medicare Part A enrollee counts and calculated 'per Part A enrollee' rates are based on enrollees in Traditional Medicare and Medicare Advantage/Other Health Plans combined, because once a beneficiary enrolled in Medicare Advantage/Other Health Plans elects the hospice benefit, his or her Medicare benefits revert to fee-for-service.		



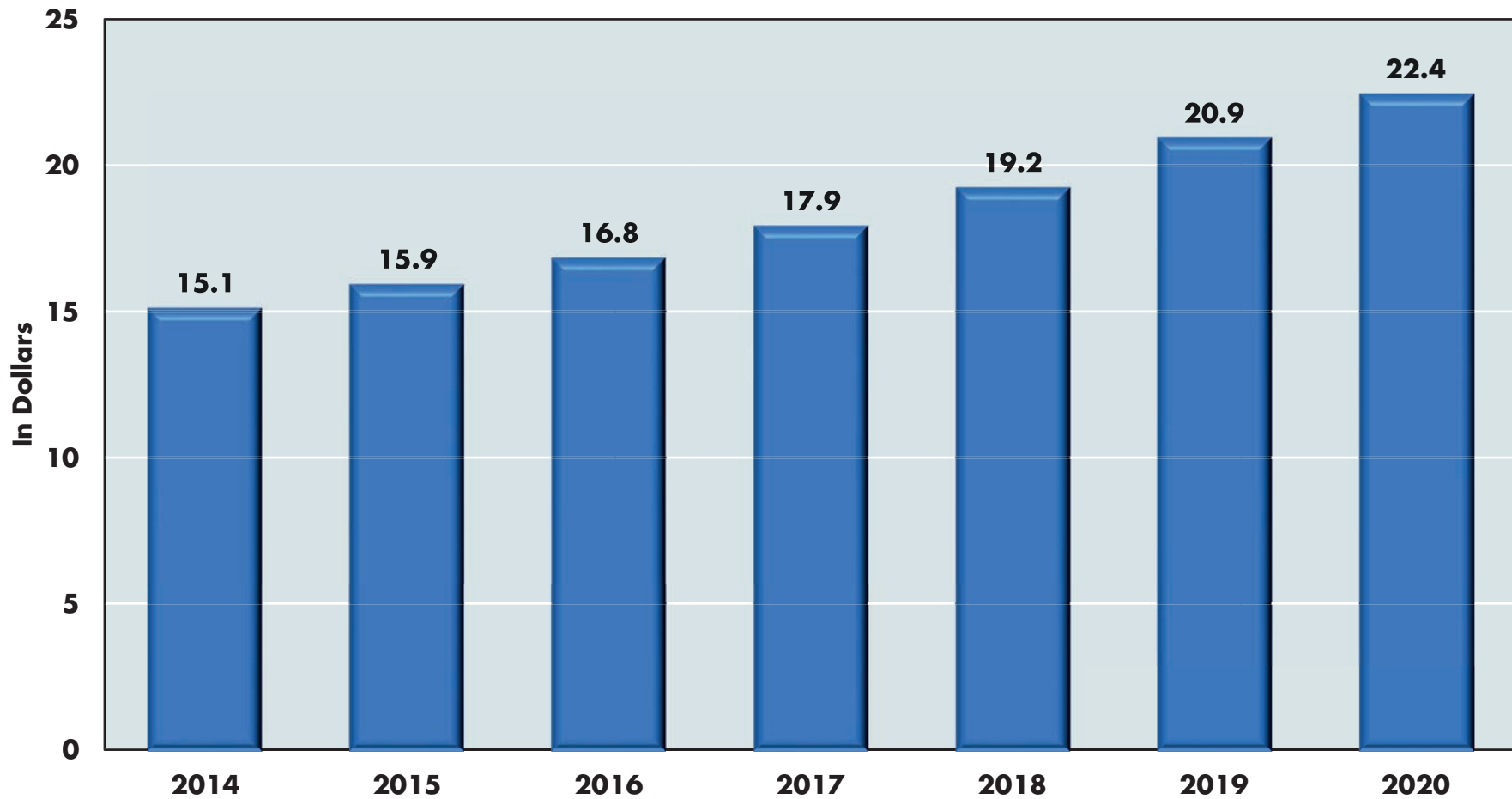
GRAPH 2
POPULATION OF MEDICARE HOSPICE PATIENTS
UNITED STATES, 2009-2020



Source: Hospice Care in America - NHPCO's Facts and Figures 2023 and MedPAC Report to Congress, https://www.medpac.gov/wp-content/uploads/2023/03/Mar23_MedPAC_Report_To_Congress_SEC.pdf

GRAPH 3

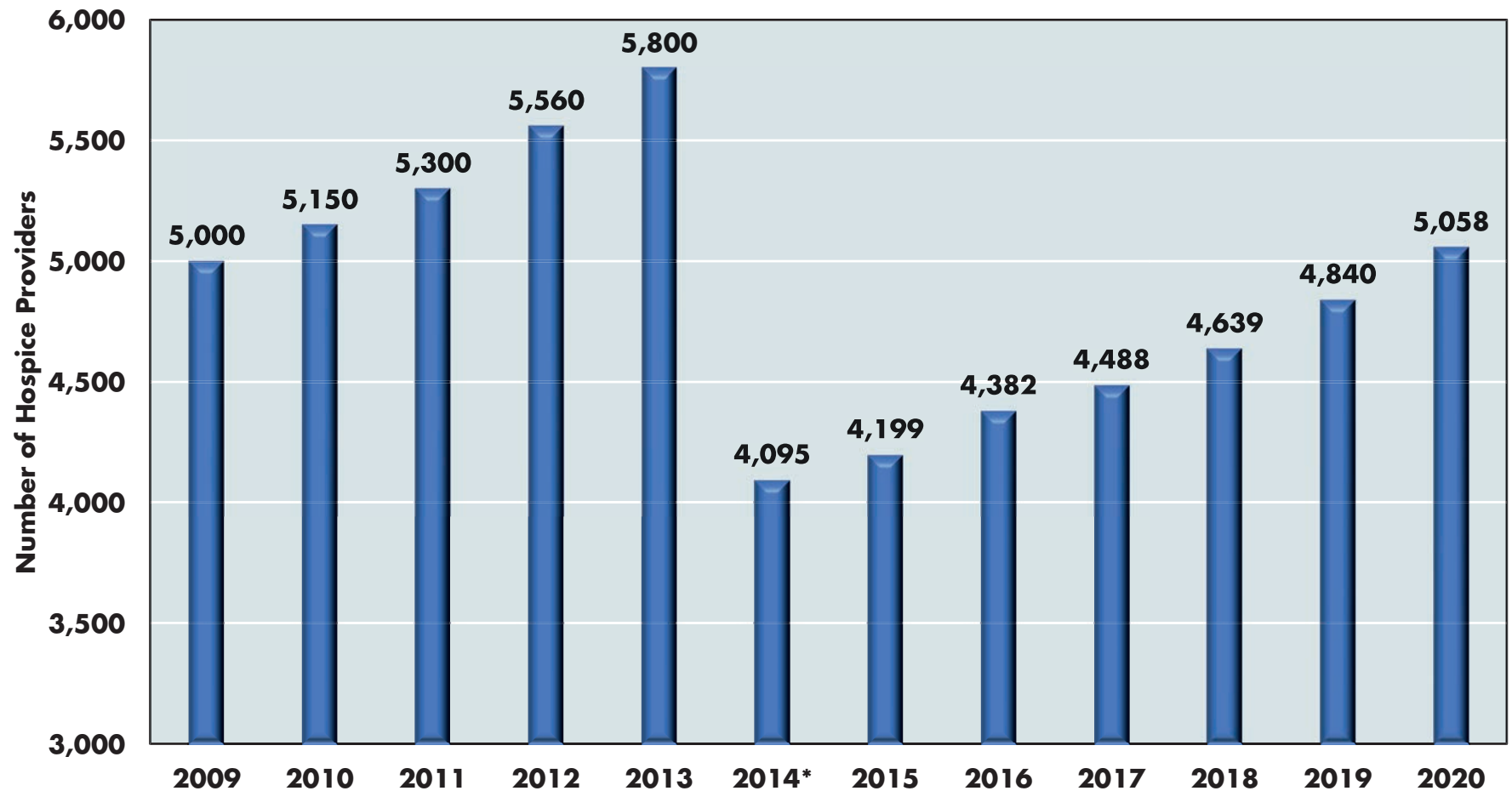
**U.S. MEDICARE SPENDING, HOSPICE, 2014-2020
(IN BILLION U.S. DOLLARS)**



Source: Medicare Payment Advisory Commission report, 2023, https://www.medpac.gov/wp-content/uploads/2023/03/Mar23_MedPAC_Report_To_Congress_SEC.pdf

GRAPH 4

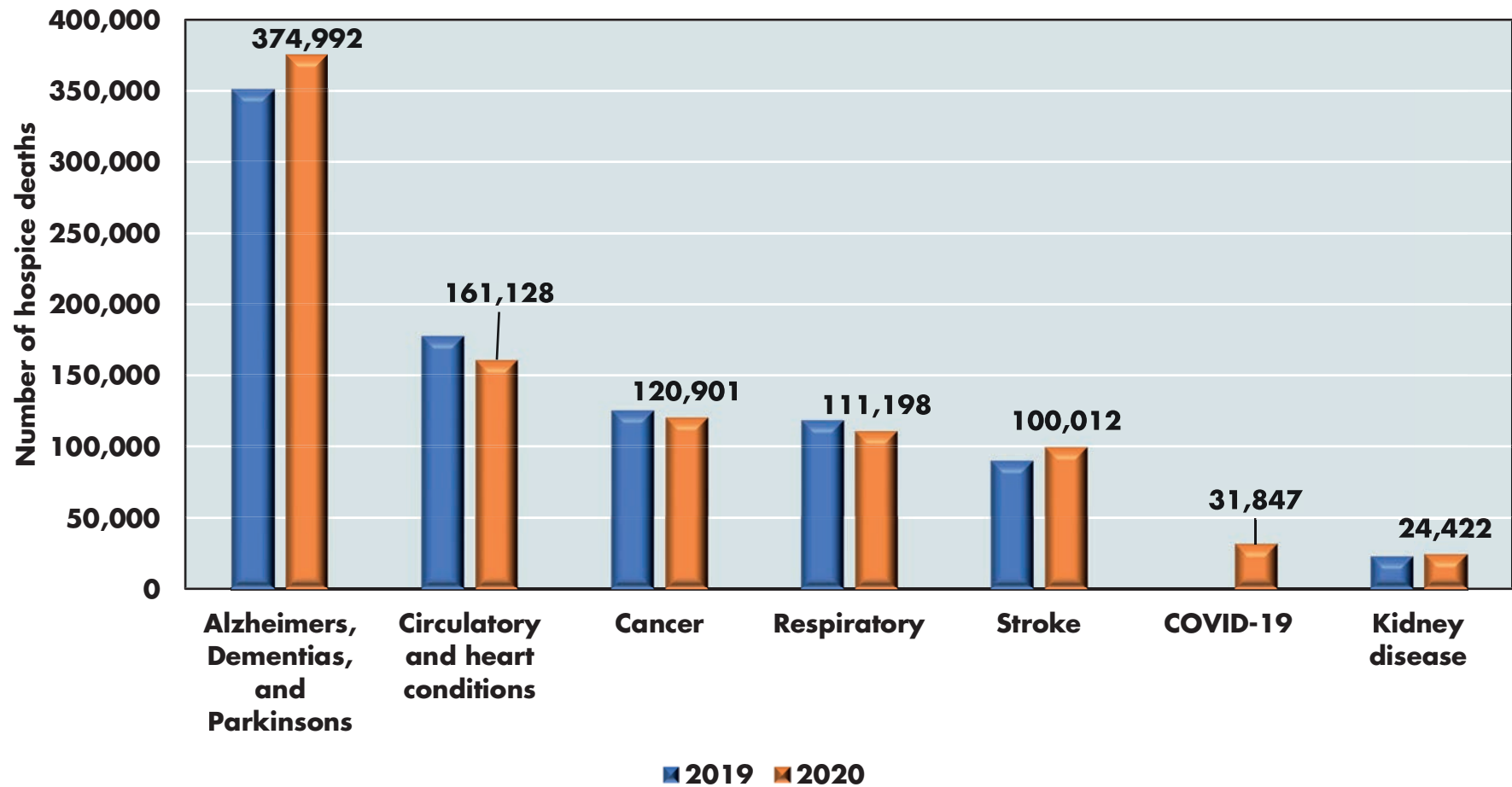
POPULATION OF U.S. HOSPICE PROVIDERS, 2009-2020



Sources: Hospice Care in America - NHPCO's Facts and Figures 2022, <https://www.nhpc.org/wp-content/uploads/NHPCO-Facts-Figures-2022.pdf> ; *Hospice providers beginning in 2014 to 2020 are Medicaid Certified Hospices.

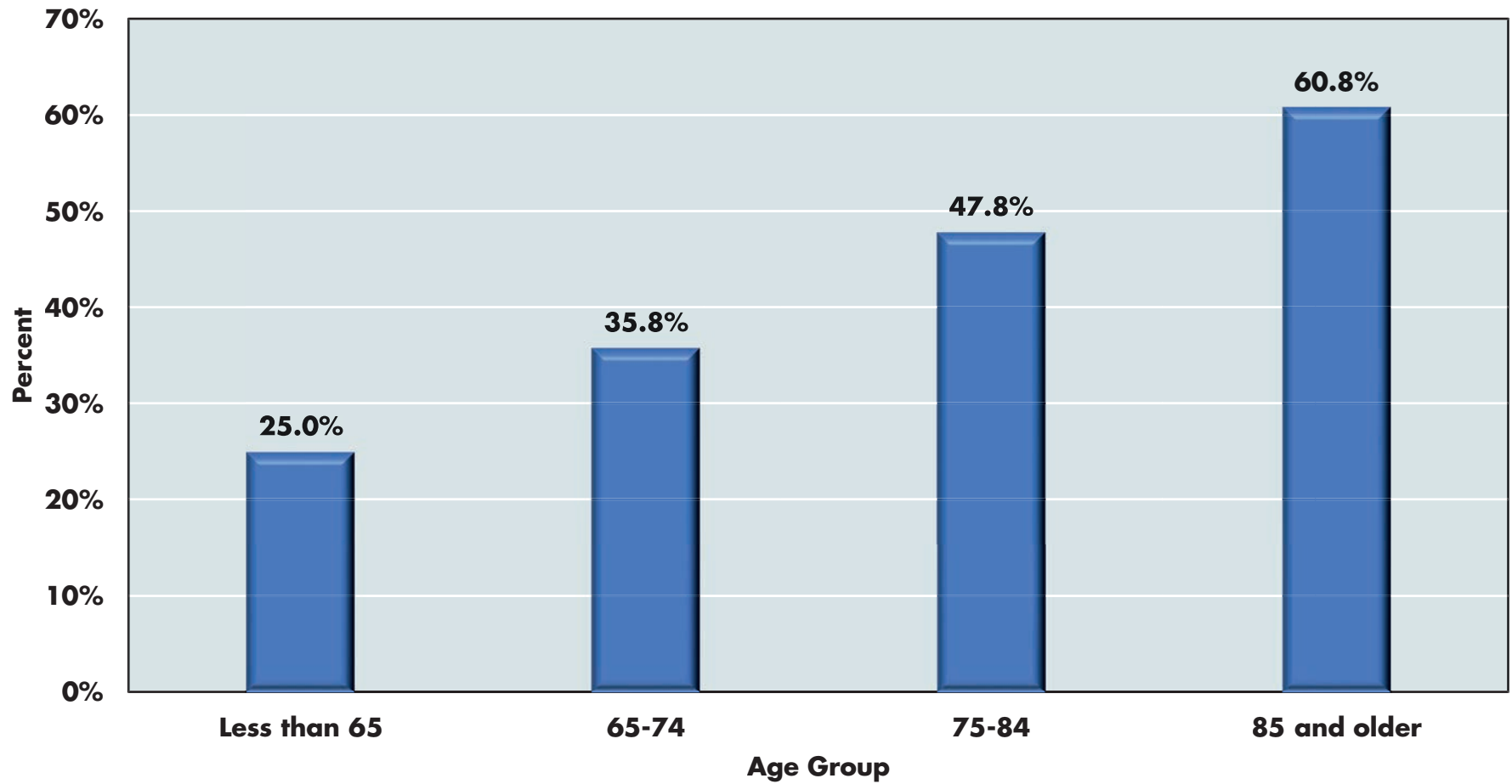
GRAPH 5

**POPULATION OF MEDICAID HOSPICE DEATHS, UNITED STATES
2019-2020, BY PRINCIPAL DIAGNOSIS**



Sources: Hospice Care in America - NHPCO's Facts and Figures 2022, <https://www.nhpc.org/wp-content/uploads/NHPCO-Facts-Figures-2022.pdf>

GRAPH 6
SHARE OF MEDICARE DECEDENTS USING HOSPICE
AGE GROUP, 2021



Source: MedPAC March 2023 Report to Congress, Table 10-3, https://www.medpac.gov/wp-content/uploads/2023/03/Mar23_MedPAC_Report_To_Congress_SEC.pdf

Hospice Care Delivered

The three most common places people at the end-of-life pass away are at home, in a hospital, or in a care facility. While not everyone may control where they will die, people who know that end-of-life is approaching may have the opportunity to plan their type of care, where they will receive it and the role of family and friends to help. Hospice care is typically provided in the patient's home, but it can also be provided in a hospice facility, nursing home, or hospital. Hospice care teams usually consist of a physician, nurses, social workers, counselors, and volunteers who work together to provide comprehensive care to patients and their families.

One of the biggest misconceptions about home hospice care (regardless of whether a private or nonprofit entity is providing the services) is that it is daily, comprehensive care. Although there are different levels of hospice care provided, the home hospice benefit primarily entails intermittent care. This implies that the care provider routinely spends less than an hour during each visit to the patient as part of their routine care. These visits may occur infrequently throughout the week or daily, and the primary burden of home hospice typically falls on family members.

Most hospice patients are eligible for Medicare. There is no deductible for hospice services although there may be a very small co-payment for prescriptions and for respite care. In most states, Medicaid offers similar coverage. It is important to note that original Medicare covers hospice even if the patient is enrolled in a Medicare Advantage Plan. Military families have hospice coverage through Tricare, and hospices will accept private payment or self-pay. End-of-life (EOL) care is usually covered by Medicare (fully covered under Medicare Part A), Medicaid, and/or a mix of private insurance plans.⁸

For the past several decades, the hospice industry has transitioned from a mostly not-for-profit sector to one where nearly 66% of all agencies operate on a for-profit basis. A substantial driver of this trend has been the growth of large publicly traded for-profit hospice chains. Facilitated by relatively easy market entry and the prospect of stable Medicare payments, these firms have made strategic hospice investments in recent years, raising numerous quality concerns among some policymakers and patient advocates, especially as many of these corporations have little experience in previously providing these services and often rely on a model of reducing care visits to cut labor costs.⁹

In a 2019 report by the U.S. Government Accountability Office presented to Congress, patients in for-profit hospices were less likely than patients in nonprofit hospices to have received any hospice visits in the last three days of life according to a 2014 to 2017 analysis of federal data.¹⁰ In *Complaints About Hospice Care in the United States, 2005-2015* published in the *Journal of Palliative Medicine* in 2018, for-profit agencies were between 1.3 and 1.5 times more likely than not-for-profits to have patients and family members complain of alleged substandard care and a deficiency. Graph 7 reports U.S. hospice ownership percentages by corporation type in 2020.

The main difference between for-profit and nonprofit hospice programs is their financial structure and the way they use their revenue. For-profit hospice programs are owned and operated by private companies or individuals who seek to make a profit. They are accountable to their shareholders and investors, and their primary goal is to generate revenue. As such, for-profit hospice programs may charge higher fees for their services, and they may be more likely to focus on marketing and profitability. Nonprofit hospice programs are typically owned and operated by charitable organizations or community groups. They do not seek to make a profit, and any surplus revenue is reinvested into the organization to support its mission. Nonprofit organizations typically have a governing board that oversees their operations and ensures that they fulfill their charitable mission. This accountability structure can help maintain high standards of care and ensure that resources are used

⁸ Details on coverage may be found at <https://www.medicare.gov/Pubs/pdf/02154-medicare-hospice-benefits.pdf> and <https://www.medicaid.gov/medicaid/benefits/hospice-benefits/index.html>

⁹ Acquisitions of Hospice Agencies by Private Equity Firms and Publicly Traded Corporations, 2020 <https://jamanetwork.com/journals/jamainternalmedicine/article-abstract/2779069>; Stevenson DG, Grabowski DC, Keating NL, Huskamp HA. Effect of ownership on hospice service use: 2005-2011. *J Am Geriatr Soc.* 2016;64(5):1024-1031. doi:10.1111/jgs.14093; Stevenson DG, Grabowski DC. Private equity investment and nursing home care: is it a big deal? *Health Aff (Millwood).* 2008;27(5):1399-1408. doi:10.1377/hlthaff.27.5.1399

¹⁰ MEDICARE HOSPICE CARE Opportunities Exist to Strengthen CMS Oversight of Hospice Providers, <https://src.bna.com/MQG>

appropriately. Nonprofit hospice programs may be more focused on providing high-quality care and meeting the needs of their patients and families, rather than generating revenue. There are also some other differences between for-profit and nonprofit hospice programs. Nonprofit hospice programs may be far more likely to provide care to patients who are uninsured or underinsured and are often deeply rooted in the communities they serve, while for-profit hospice programs may focus more on patients who have private insurance or Medicare.

In the 2019 *State-by-State Report Card on Access to Palliative Care in Our Nation's Hospitals* published by the Center to Advance Palliative Care (CAPC) and the National Palliative Care Research Center (NPCRC), the U.S. exhibited continued growth in the overall number of hospital palliative care teams with 72% of U.S. hospitals with 50 or more beds reporting a palliative care team. These hospitals served 87% of all hospitalized patients in the United States. CAPC researchers present geographical differences, the status of for-profit or nonprofit hospitals, and hospital size as factors deeply impacting the quality of patient care for those living with a serious illness.

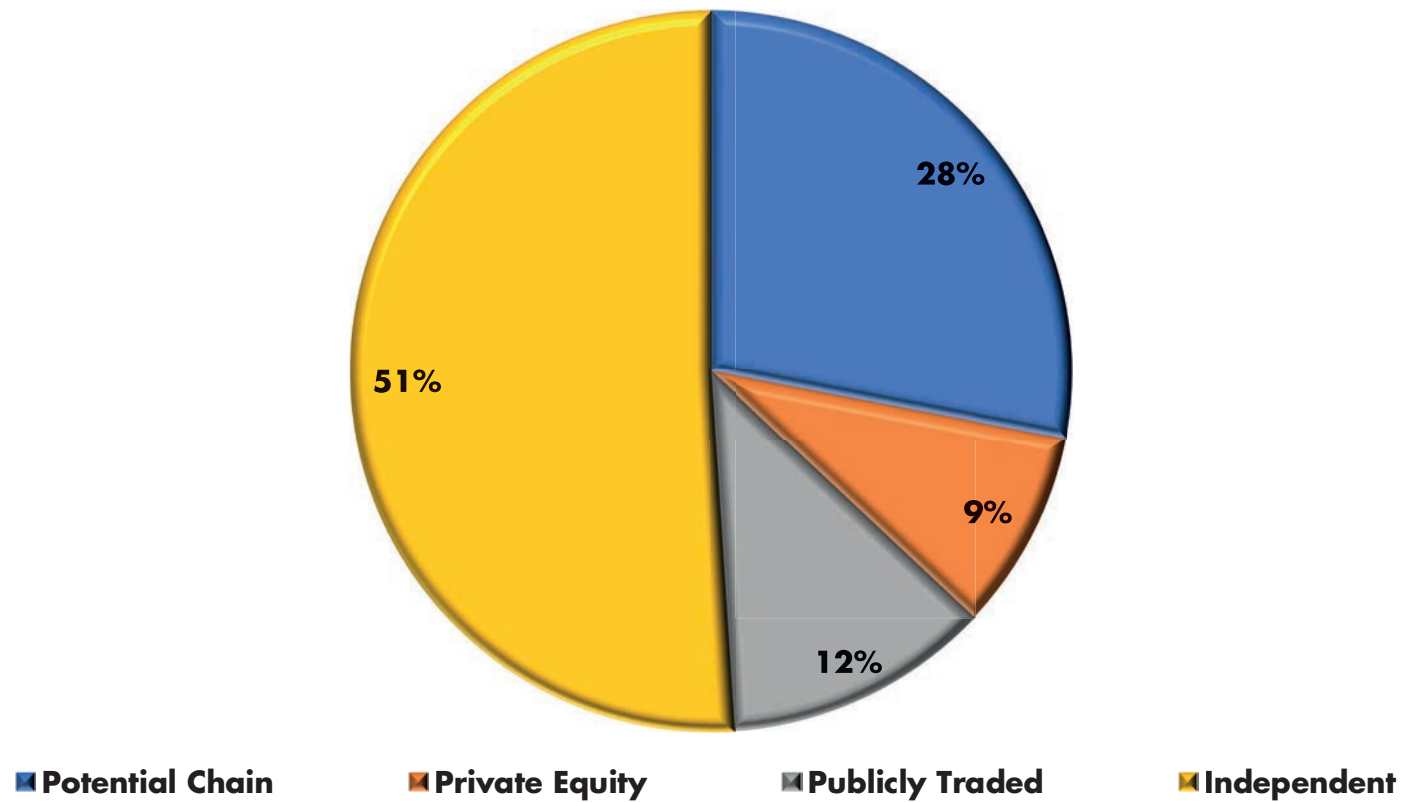
One of the key findings of the report is that access to palliative care is still unreliable in the U.S. and that nonprofit hospitals are more far likely than for-profit hospitals to provide palliative care. Virginia received a letter grade of A/86.5,

and Table 4 details the Commonwealth's ranking in the 2019 report. The Virginia Association for Home Care and Hospice has renewed calls for additional sources of funding and support for palliative care and training including more non-physician professionals such as palliative nurses. Citing the American Academy of Hospice and Palliative Medicine, the organization states that over the next 20 years, the demand for palliative care will grow by more than 20%, while over the same time, the palliative physician workforce will grow by only 1%.

It is important to note that the previously mentioned distinctions do not imply that all for-profit hospice providers are deficient or that all nonprofit providers are superior. There are excellent organizations on both sides of the spectrum. The aim of highlighting the differences here is to provide patients and family members with the necessary information to make an informed decision based on their preferences, values, and the specific qualities they seek in a hospice care provider. Transparency and accountability can promote higher quality hospice care.

TABLE 4									
PALLIATIVE CARE PROGRAMS IN U.S. HOSPITALS, VIRGINIA, LETTER GRADE, 2019									
Limited to U.S. Hospitals with 50 or More Beds									
State	Letter Grade	Number Grade	Total Programs/ Hospitals	By Hospital Type			Sale Community Provider	>300 beds	<50 beds*
				Nonprofit	For-Profit	Public			
Virginia	A	86.5	(45/52)	97.4 (38/39)	40.0 (4/10)	100.0 (3/3)	60.0 (3/5)	100.0 (15/15)	45.0 (9/20)
Source: https://reportcard.capc.org/Note : Additional data on hospital palliative care programs were obtained from the National Palliative Care Registry™ (registry.capc.org) and CAPC's Mapping Community Palliative Care initiative (mapping.capc.org).									

GRAPH 7
MEDICARE HOSPICE BY
CORPORATE OWNERSHIP PERCENTAGE, UNITED STATES, 2020



Source: 2022 State Hospice Report, Hospice Analytics https://www.nationalhospiceanalytics.com/library/2022_State_Hospice_Report_2020_Medicare_Data.pdf

What's missing in Hospice Care in Hampton Roads

It is important to note that while there may not be a shortage of hospice care overall in the United States, there are specific communities, particularly in poor and/rural areas, which do not have adequate access to hospice services.¹¹ The majority of hospice patients are cared for by unpaid and often untrained family caregivers. The need for family members willing to serve as caregivers for their loved ones is anticipated to grow exponentially as the nation's population ages. The CDC has called the impending caregiver shortage, compounded by the COVID-19 pandemic, an emerging public health crisis. Addressing these disparities in access to care is an important goal for the hospice industry and healthcare system as a whole, especially as our population ages.

The latest data available on hospice care across the United States suggests that the Hampton Roads region appears to be the largest Metropolitan Statistical Area (MSA) in the nation without a freestanding hospice house. The single nearest comparable facility, Hospice House of Williamsburg, is a community-supported home identified as a Social Model Hospice Home (SMHh). What are free-standing or independent hospices? Free-standing or independent hospices are specialized healthcare facilities or organizations that provide end-of-life care and support to patients with terminal illnesses and their families. Unlike hospice services that are affiliated with or operated within a hospital or healthcare system, free-standing or independent hospices operate as separate entities that exclusively serve individuals within six months of death.

As previously mentioned, hospice care is often primarily intermittent care, daily and/or weekly visitations that are usually less than an hour in length. In fact, it is important to know that seriously ill patients usually require someone at home with the patient 24 hours a day, 7 days a week, and this can dramatically

impact the patient's family. Unfortunately, in-home visits by hospice workers and part-time caregivers do not work well for many patients and their families. On-site hospice services at home are not 24/7, and this means that family caregivers are responsible for most of the care needs including administering medications, providing personal care, and coordinating health services – most of whom do not feel comfortable or qualified to do so. All too often, family members quickly run out of work leave to coordinate and administer care from home. Patients deserve to have their symptoms and pain addressed quickly by medical experts to maximize the quality of life that remains. Additionally, many patients do not want their families traumatized by their death in the home.

Around the United States, many communities have freestanding inpatient hospice facilities to assist individuals who do not have caregivers available at home or need around-the-clock physical care. In many states, respite care (temporary care by someone other than their primary caregiver) is often provided at inpatient hospice facilities. Another benefit of an inpatient hospice facility is that they are designed to provide a peaceful and comfortable environment for residents. They often offer private rooms, family gathering spaces, gardens, and amenities like massage therapy, music therapy, and pet therapy. These amenities contribute to the well-being and comfort of residents and their families. The vast majority of hospice houses need ongoing charitable support or endowments to operate.

Virginia has only eight hospice houses in the entire state, far fewer per capita than neighboring states. For example, West Virginia has a hospice house for every 30,000 citizens. More than 1.8 million citizens in Hampton Roads currently have no freestanding hospice house to meet their end-of-life needs. In 2020, MSA data analysis found that Raleigh, NC, (Wake County) and Hampton Roads were relatively comparable markets in median age, household income (HHI) and overall population. They serve similar demographic groups, and both do not have enough freestanding hospice houses to meet the needs of their residents. However, the vast difference between our area and Raleigh is that in 2009, a freestanding 20-bed hospice house, the William M. Dunlap Center for Caring – “Hospice Home” – was opened in Cary after the North Carolina Council of State awarded 8.7 acres of land for the project. All

¹¹ See Hospice and palliative care access issues in rural areas. Am J Hosp Palliat Care. 2013;30(2):172–177.

patients are served regardless of ability to pay or insurance status, with donations covering uninsured costs. In 2017, based upon overwhelming need, an additional 10-bed wing was added to serve the population after an aggressive “Power of 10” capital campaign. In 2018, at the 40th anniversary of the Hospice of Wake County (HOWC)/Transitions LifeCare’s work in Wake County, medical and caregiving teams reported serving 570 hospice patients, 100 Home Health Patients, 870 Palliative Care patients, and 51 children in the Transitions Kids program *daily*.¹²

In January 2020, an independent study of the business case for a freestanding hospice house in Hampton Roads was completed. The study identified the need for at least 45 inpatient beds in Hampton Roads. Figure 1 reports on this need.

An organized network of dedicated health professionals, business leaders and concerned citizens are responsible for the \$9.56 million Dozoretz Hospice House of Hampton Roads breaking ground in 2022. Under construction, it will address an urgent need to care for the region’s terminally ill patients in a specialized setting.

The Dozoretz Hospice House of Hampton Roads will be the region’s first freestanding inpatient hospice home and is expected to open in early 2024. The city of Virginia Beach contributed 2.5 acres of land and through a series of significant donations, the 501(c)(3) non-profit facility will open and operate in the Red Mill neighborhood. The hospice house will offer 12 private bedroom suites for patients and will include a screened porch, chapel, living room with fireplace, and a kitchen. Family will have 24/7 access to the facility to spend time with their loved one. Professionally licensed medical personnel, along with trained volunteers, will staff the facility. The Hospice House staff members will be available 24 hours a day, 365 days a year. It will be the mission of the staff

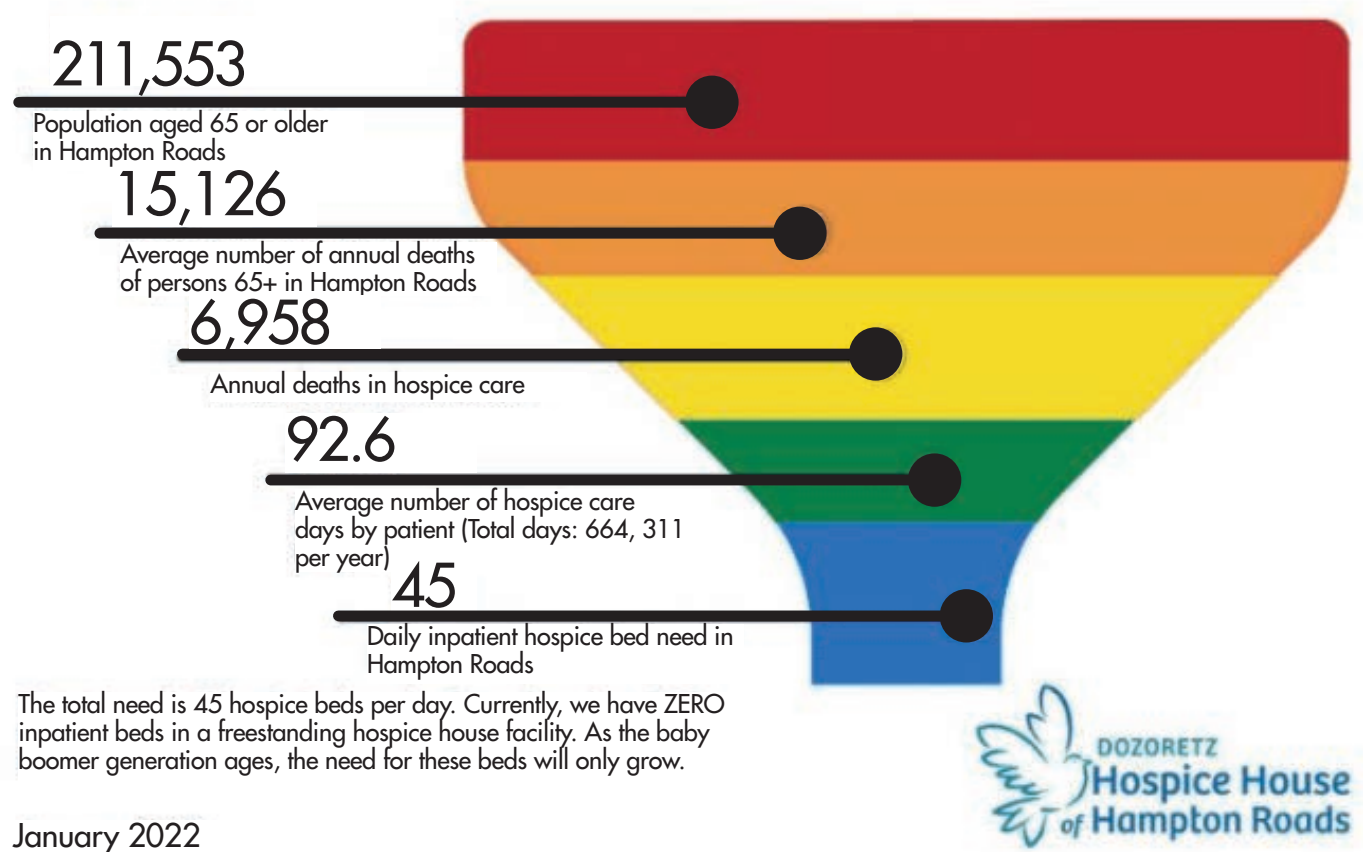


The Dozoretz Hospice House of Hampton Roads (DHHHR), www.hospicehousehr.org

to walk side-by-side with patients and offer support, not only for any physical symptoms, but for emotional and spiritual needs too. This support will extend to family members and friends. The DHHHR will partner with Westminster-Canterbury on Chesapeake Bay (WC) and Beth Shalom Village. WC will manage the medical care and daily operations of the hospice house. Beth Shalom will oversee the billing and account management.

¹² <https://www.transitionslifecare.org/patients/hospice/hospice-home/> Note: Hospice of Wake County (HOWC) changed names to Transitions LifeCare in 2013.

FIGURE 1
UNMET NEED OF HOSPICE BEDS IN HAMPTON ROADS
2020



Source: Dozoretz Hospice House of Hampton Roads

Dr. Paul F. Schellhammer, retired urologist and immediate past chairman of the Dozoretz Hospice House of Hampton Roads Board of Directors, told us that “most importantly, hospice care is not giving up hope or hastening death. Instead, it is choosing to celebrate what time patients have left and making them as comfortable as possible. For their family, it means spending quality time with their loved ones instead of having to focus on caregiving and other daily tasks that are required in a home hospice setting.” Marissa Galicia-Castillio, MD, Director, EVMS Glennan Center for Geriatrics and Gerontology, told us, “We have patients and families that need this hospice house because they don’t have the resources to stay at home. Our practice has several patients a month with this unmet human need. I joined the DHHR’s board because I strongly believe we need a place where family members have the support to truly be present for their loved ones whose time may be short.” All too often, the burdens are great for family members, and some run out of leave from their work to coordinate and administer care from home. Additionally, many people, especially older adults today, do not have close friends or relatives nearby to help with their care. Inpatient hospice care in a Hospice House provides support in these situations, ensuring no one dies alone.

A new freestanding inpatient hospice home in Hampton Roads brings end-of-life care closer to the community. Although located in Virginia Beach, this facility will serve our entire region. This allows patients to receive care in a familiar setting, surrounded by their loved ones and within their local community. It fosters a sense of belonging and support, as individuals may have established connections and relationships within the community that can be strengthened during their end-of-life journey. In addition to providing hospice beds, Dozoretz Hospice House will operate a Bereavement Center that will serve families and their loved ones. Bereavement is the time of mourning after a loss. The bereavement care team will work with loved ones to help them navigate the grieving process. Trained volunteers, clergy members and professional counselors will provide personalized support for at least a year after a patient’s death. The establishment of the home in Hampton Roads is a positive development as it improves access to specialized care, enhances the quality of care provided, supports caregivers, offers emotional and psychosocial support, and brings community-centered care to individuals facing end-of-life circumstances.



A patient's suite equipped with a private patio and a couch for family members to stay overnight in the Dozoretz Hospice House. Artist rendering: <https://www.hospicehousehr.org/new-page>

Local Specialized Services for the Dying

Some readers may be familiar with a traditional Doula, a trained professional who provides physical and emotional childbirth support to an expectant mother in labor. A more unusual type of Doula has emerged in the last 10 years, known as an End-of-Life (EOL) or Death Doula.¹³ These doulas are trained professionals that assist an individual in their end-of-life days. EOL doulas specifically assist with the needs of the dying person. This may include talking with the person about dying “including how dying may feel” and what they may experience, helping them identify their final wishes including a plan for what they want after their death. Doulas can also assist in communicating with

family members and friends as well as creating memories and writing final letters before passing forward. Doulas are different from hospice or palliative care in that they do not provide medical services, medical evaluations and medications for comfort and pain. However, Doulas may be on the staff of a Hospice Team. Amy Nixon of Comforting Hands in Newport News provides compassionate end-of-life doula care. “My focus is on bringing total physical, informational, and emotional support to my clients and their loved ones. As death is imminent, I sit vigil with the caregiver and/or loved ones. This is usually the hardest part for everyone, and here I provide gentle guidance and support. Emotions can run high, and loved ones often don’t know quite what to do. It is here that I can help turn an anxiety and fear-filled experience into a meaningful one.” Table 5 provides a directory of selected Doulas in our region.

TABLE 5

SELECTED END-OF-LIFE DOULAS, HAMPTON ROADS

NAME	PHONE	EMAIL	LOCATION	SERVICE AREA
Sade’ Combs	804-210-0030	-	Richmond	Richmond, Hampton Roads
Cryst’l Gatto	503-781-6909	Cryst.l785@gmail.com	Lanexa	Williamsburg
Krystal Giordano	-	deathdoula@etadmirations.com	Virginia Beach	Hampton Roads
Anisa Glowczak	757-572-4609	goodmourningcc@gmail.com	Virginia Beach	Hampton Roads
Dr. Michelle Joachim	757-642-1396	MichelleNJo@gmail.com	Chesapeake	Hampton Roads
Amy Nixon	757-987-5991	amy@comfortinghands.net	Newport News	Hampton Roads Peninsula
Ann Petty	757-985-7377	ann.petty.r@gmail.com	Virginia Beach	Hampton Roads
Ashley White	304-308-0123	ashleynicole046@hotmail.com	Newport News	Hampton Roads

¹³ Readers may prefer “end-of-life” doula rather than “death” doula as some cultures are uncomfortable with the term “death”. By offering the term “end-of-life doula,” it allows for a more inclusive and adaptable approach to support. Some people may feel more comfortable with a term that focuses on the entire end-of-life journey rather than solely on death, aligning with diverse personal and cultural perspectives.

Final Thoughts

Talking about serious illness, hospice care, and EOL matters can be challenging for several reasons. Death and dying are often considered uncomfortable topics in American culture. There is a general societal reluctance to openly discuss these subjects, which can create barriers to meaningful conversations about EOL decisions. There is fear and denial, and many individuals fear facing their mortality or the mortality of their loved ones. This fear, combined with a natural inclination to deny the inevitability of death, can make it difficult to broach the topic and engage in discussions about serious illness and end-of-life care.

In the United States, there is a strong emphasis on medical interventions and the pursuit of curative treatments. This focus on “fighting” illness and extending life can overshadow conversations about the limitations of medical interventions and the importance of quality-of-life considerations, including hospice care. There is also a widespread lack of awareness and understanding about hospice care and end-of-life options. The American healthcare system is often criticized for its fragmentation, which can impede effective communication and coordination of care. This fragmentation can make it challenging for patients, families, and healthcare providers to navigate the complex landscape of serious illness and end-of-life decision-making. Compounding the confusion is that many people are unaware of the available benefits and availability of no- or low-cost hospice services, leading to a lack of proactive discussions and planning for end-of-life. Unfortunately, there is evidence that substantial proportions of patients (especially in rural areas) have only pursued hospice care late in the dying process, which is not uncommon.¹⁴

We are a diverse nation with a wide range of cultural and religious beliefs surrounding death and dying. These diverse perspectives can influence attitudes toward discussing serious illness and end-of-life care, leading to varying levels of comfort and difficulty in addressing these topics. When death becomes a taboo topic within a family, it can create emotional isolation for individuals who may need support during difficult times. If someone is grieving or facing a terminal illness, the inability to openly express their emotions and fears can lead to feelings of loneliness and increased psychological distress. Avoiding discussions about death can lead to family disagreements and conflicts when critical decisions need to be made. Different family members may have varying perspectives on medical treatments which can cause tension and strain relationships. EOL decisions, such as advance care planning and the use of medical interventions, can involve complex legal and ethical considerations. Varying state laws, confusion surrounding terminology, and ethical dilemmas related to issues like withholding or withdrawing treatment can add layers of complexity to these discussions.

Overcoming these numerous challenges requires promoting open dialogue, increasing public education about hospice and end-of-life options, improving healthcare communication and coordination (especially in underserved communities) and fostering a cultural shift that normalizes conversations about serious illness and end-of-life care. Creating supportive environments that encourage and facilitate these discussions can help individuals and families make informed decisions and receive the appropriate care and support during these important life stages. Promoting societal awareness of EOL care helps combat the stigma often associated with serious illnesses, including cancer. By encouraging open discussion and understanding, individuals facing heart disease, cancer, kidney failure, chronic obstructive pulmonary disease and other serious conditions are less likely to feel isolated or judged. Increased awareness fosters compassion and empathy, creating a more inclusive and supportive environment for those affected.

¹⁴ Baernholdt M, Campbell CL, Hinton ID, Yan G, Lewis E. Quality of hospice care: comparison between rural and urban residents. *J Nurs Care Qual.* 2015 Jul-Sep;30(3):247-53. doi: 10.1097/NCQ.000000000000108. PMID: 25546093; PMCID: PMC4582410 and Robinson CA, Pesut B, Bottorff JL. Issues in rural palliative care: Views from the countryside. *J Rural Health.* 2010;26(1):78-84.

Hospice services provide a valuable benefit. The goal of hospice care is to provide patients with the highest quality of life possible, while also supporting their families and caregivers during a challenging time. Hospice care emphasizes comfort, dignity and respect, and it can be a valuable resource for patients and families facing the end-of-life. The economic impact of hospice care is also clear. **In the *Value of Hospice in Medicare* report presented by NORC at the University of Chicago, the total costs for Medicare beneficiaries who used hospice care in the last year of life was 3.1% lower than for those beneficiaries that did not use hospice.** Hospice care is often more cost-effective compared to aggressive medical interventions or prolonged hospital stays. By shifting the focus from curative treatments to comfort care, hospice can reduce unnecessary hospitalizations, emergency room visits, and intensive care utilization. This not only lowers healthcare costs but also helps patients and families avoid financial burdens associated with extensive medical interventions.

In 2024, the Dozoretz Hospice House of Hampton Roads will finally serve our community as the region's first freestanding inpatient hospice home. This achievement is a testament to the dedication and tireless efforts of numerous individuals, organizations, and the larger community to provide much-needed services to our citizens. As hospice care expands in our region, we can expect a greater level of community engagement and awareness regarding end-of-life matters. This increased understanding will encourage open dialogue, reduce the stigma surrounding death and dying, and empower community members to have proactive discussions and make informed decisions about their end-of-life care.

Having a hospice house in our region is a tremendous achievement that will positively impact the lives of many individuals and their families. The hospice house will complement the efforts of our region's hospitals and home hospice providers in providing care for end-of-life residents. The hospice house means that people facing serious illnesses will now have access to another form of specialized care and support in their final stages, ensuring their comfort and dignity. Expanding hospice care in our region not only brings about improved quality of life for individuals but also offers economic and healthcare benefits. By reducing unnecessary hospitalizations and intensive care utilization, hospice can promote a more efficient and coordinated healthcare system, benefiting patients and healthcare providers alike.

In the face of tough issues, especially death and dying, it is our willingness as a community to confront and tackle them head-on that unveils our true strength and resilience. For it is through these courageous conversations and actions that we pave the way for progress, understanding, and the best care for members of one of our most vulnerable populations.

