



# Capital Caring Health

*Advanced Home Care & Hospice for All Ages at All Times*



## Your Guide to Choosing a Hospice

*Making the Best Choice for You and Your Family*

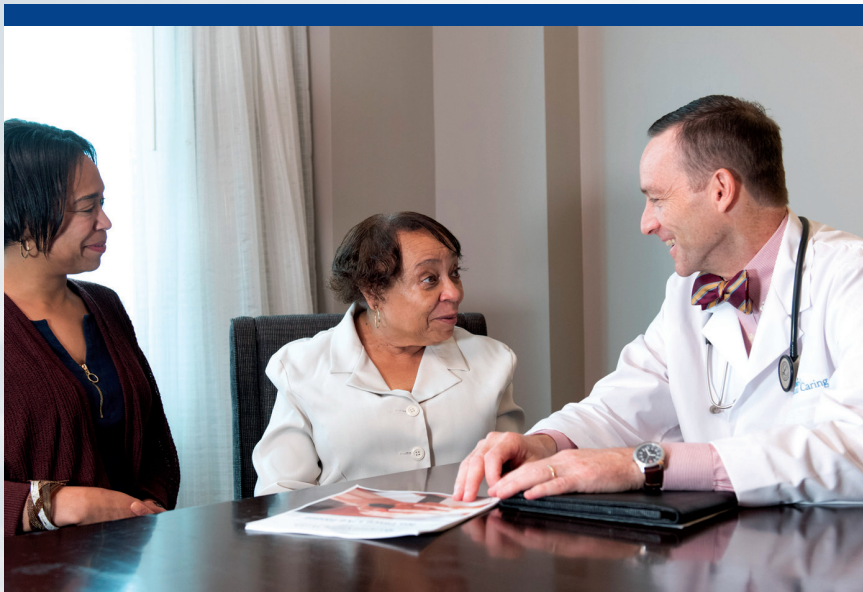
## About this Guide

This guide is provided to you as a courtesy from Capital Caring Health (CCH), the largest and oldest non-profit provider of hospice and advanced illness care in the mid-Atlantic.

A leader in the field, CCH has collaborated with The National Partnership for Hospice Innovation (NPHI) to develop this guide. By discussing key topics, it is designed to help you make an informed evaluation as you consider hospice care for a loved one.

As an added benefit, the guide is accompanied by a checklist for your use in discussions with hospice staff and others.

We hope both tools help you gain valuable information about the hospice or hospices you may be considering so you can make the very best decision for this important stage in life.



## Your Guide to Choosing a Hospice

### *Making the Best Choice for You and Your Family*

**Among the many life decisions**, you may ever have to make, choosing a hospice for end-of-life care for yourself or a loved one is among the most important. And it's a decision that must be made at a challenging and emotional time.

While only you and your family can decide what's most important based on your unique circumstances, values and wishes, this guide is designed to help you select the hospice that's best for you and your family.



## The Key Differences Between Non-profit and For-profit Hospices

Generally, hospices are either run as for-profits, designed to generate a financial return to shareholders, or non-profits, which basically reinvest any funds left over after expenses back into the organization and its mission. While both provide the same type of care, there are some important distinctions between the two.

In particular, a recent study\* shows key differences in how they spend their money, with for-profit hospices directing fewer funds to patient services than non-profits. When it comes to bereavement support, for example, non-profit hospices devote nearly twice as much as their for-profit counterparts. For-profits also spend more on items unrelated to patient care, including 300 percent more on advertising than non-profits.

By comparison, the study found that non-profit hospices put more of each dollar directly into hospice care, patient and family support, translating into:

10%

more nursing visits

35%

more social worker visits

2X

as many therapy visits per patient day as for-profit hospices

Other differences include the types of patients cared for. Non-profit hospices generally take on more complicated patients, as a larger percentage enroll directly from the hospital, and are more labor-intensive and expensive to care for. As part of their mission, non-profit hospices also provide care at no cost for some patients who lack insurance coverage or other financial means. No one is ever denied needed care.

**The bottom line:** Whether a non-profit or for-profit, every hospice should be able to tell you how much of each dollar is spent on direct patient care and family support. Hospices that offer charity care for those who could otherwise not afford care should be able to tell you what they spend and their criteria for providing financial help.

As a non-profit, Capital Caring Health (CCH) spends almost 90 cents of every dollar raised directly on patient care and family support. Altogether, we provide \$3 million annually in patient care and services to families without coverage or other financial means to assure that all receive the care they need.

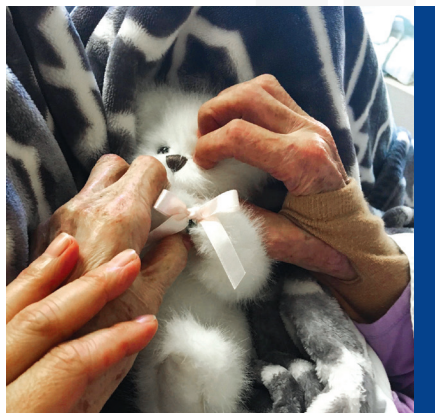


## Understanding Hospice

Hospice is a philosophy of care designed to provide comfort and improve quality of life for someone diagnosed as having six months or less to live. A major focus is controlling pain and other symptoms, and providing emotional, social and spiritual support for patients and their families.

### The types of conditions that most often lead to hospice care include:

- Cancer
- Congestive heart failure (CHF)
- Alzheimer's and other forms of dementia
- Stroke and other neurological conditions such as ALS or Parkinson's
- Lung disease including COPD and other progressive conditions



Typically, 98 percent of hospice care is delivered in the home, although it may also be provided at other settings such as free-standing hospice centers, assisted living facilities, or local nursing homes or hospitals that have an arrangement with the hospice. Whether in the home or another setting, each patient has a dedicated interdisciplinary care team to provide medical care and social supports based on the individual care plan developed following referral.

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**It is important to note** that hospice care is not a replacement or alternative to the primary caregiver role of family or friends. Instead, hospice staff work with caregivers, training family members in how to meet patient care needs, including pain management, along with providing emotional and social support through counseling, companionship, and, where appropriate, short-term respite care. Light housekeeping, help with errands, and other activities are also available.

According to several studies, families report wishing they had known sooner about hospice care. Other studies also show that hospice care may actually extend life—up to 28 days—in some cases.\* To get the greatest benefit for patients and families, it is better for the patient to be enrolled for at least two to three months, so he or she can receive comfort care...not crisis care.

\*Connor SR, Pyenson B, Fitch K, et al. Comparing hospice and nonhospice patient survival among patients who die within a three-year window. [Journal of Pain Symptom Management. 2007;33\(3\):238-246.](#)

## How Much Does Hospice Cost?

**Both Medicare and the VA cover all hospice costs.** Coverage under health plans, commercial insurance and Medicaid may include small co-payments.

As most hospice patients are Medicare beneficiaries, Medicare imposes certain requirements on any hospice that wants Medicare reimbursement. Other plans that offer hospice coverage typically follow suit.

### To be Medicare-certified, a hospice must feature:

- A specialized team of nurses, home health aides, social workers, chaplains, supervising physicians, nurse practitioners and others
- Around-the-clock, on-call support
- Medical equipment and supplies, such as wheelchairs, hospital beds, oxygen and more, delivered to the home
- Medications to control symptoms and pain
- Dietary counseling, physical, occupational or speech therapy, as needed
- Short-term care in a specialized hospice facility for medically necessary reasons
- Short-term respite care (up to five days) in a facility for those times when family is either unavailable to provide care
- Counseling support and guidance for patients, families and caregivers

**A Medicare beneficiary must select a Medicare-certified hospice like Capital Caring Health if they want their Medicare hospice coverage to take effect.**

## What to Look For

To begin, you'll need to determine what hospices are available in your geographic area. A good place to start is by checking the website of your local Area Agency on Aging.

You may also want to ask for referrals from trusted sources including:

- Your doctor, family physician or specialist, nurses or other healthcare professionals
- Therapists, social workers or clergy
- Friends or neighbors who have direct experience with hospice care

Most hospice websites also provide useful and detailed information including the areas they serve, how the referral process works, services and support provided and much more.

To consider whether a specific hospice is the right choice for your needs, you may want to talk or meet with hospice staff. All have a toll-free number you can call any time, day or night, to learn more about the organization and their services. Most also offer a free in-person physician consultation in the home, hospital, or nursing home, before hospice coverage is elected.

While every patient and family situation is different, there are common characteristics to look for in a hospice—experience; demonstrated commitment to direct patient care and family support; timely access to services, and transparency. Every hospice should be able to answer your questions.

### Some other factors to consider are:

**Hospice Accreditation:** While hospices are not required to be accredited, earning accreditation signals that a hospice has gone above and beyond the standards required for Medicare with a third-party review of their care. The three national organizations that apply defined quality standards are:

- Accreditation Commission for Health Care, Inc. (ACHC)
- Community Health Accreditation Partner (CHAP)
- The Joint Commission



**Staff credentialing/accreditation:** Clinical staff members of the hospice care team include doctors, nurses, physician assistants, and social workers. Advanced, specialized training in hospice and palliative care is recognized through certification or accreditation.

**Personal experiences of other patients, families:** Many hospice web sites feature personal videos or stories from patients and family members who have used their services, or you can ask if the hospice can arrange for you to talk to a family member or caregiver of a former hospice patient.

**Short-term, in-patient care capabilities:** Occasionally, a patient may need more intensive, short-term care than what a hospice can provide in the home. At other times, the primary caregivers may be temporarily unavailable or unable to provide care, leaving the patient with nowhere to go. Check to see what interim, in-patient care options the hospice offers.

**Accredited by CHAP,** Capital Caring Health has the region's largest concentration of board-certified professionals. Our physicians, nurse practitioners and physician assistants are board-certified, advanced-certified or specialty-trained in hospice and palliative medicine. Our licensed counselors also have specialized training in advanced illness care.





## What Services Are Offered?

To meet Medicare requirements, hospices must provide:

- Comprehensive care and support from training family and caregivers on patient care, to food preparation and light housekeeping, to companionship and respite care
- Clinical staff available 24/7 to answer any questions by phone, or visit in person, as needed
- Emotional and spiritual support for family and caregivers to help with stress and anxiety through counseling and peer support groups led by trained staff

Beyond meeting basic requirements, actual services may vary, so ask about specifics that are important to you.

**Examples of specific specialized services are:**

**Care for Children, Veterans:** If your loved one is a child or a veteran or has other special circumstances such as complex pain issues, make sure that the hospice has the services you need. For instance, not all hospices accept pediatric patients. And while some may provide palliative and hospice care for children, only a few have a formal pediatric practice with a specialized team in place. Similarly, while many hospices take care of veterans, the extent of services may vary.

**A Strong Volunteer Program:** All hospices are required to use volunteers; however how they are trained and put to use may differ. In some hospices, volunteers may be restricted to providing companionship and performing light housekeeping while others have advanced training for bereavement support. During your search, try to determine how volunteers are screened, trained, and matched with families.

**Bereavement Support:** Medicare requires hospices to provide standard bereavement services to caregivers for up to a year. Individual hospices, however, can choose what type of support to offer, from phone calls to written materials to support groups. As a result, the nature and extent of services varies, so ask for details.

## Capital Caring Health Hospice Care and More

*Going Above and Beyond*

Capital Caring Health exceeds requirements across the board... from add-ons to core services...to specialized care for children and veterans...to comprehensive bereavement support.

## Special Services and Support



**Children's Hospice and Palliative Care:** We're one of the country's oldest and largest providers of hospice and palliative care for children with complex medical and family needs. Because this level of care calls for advanced training and experience, we also partner with National Children's Medical Center—one of the country's leading pediatric hospitals.



**Veteran's Health & Support Services:** By working with VA services agencies, CCH helps veterans get the special, often service-related care and support they need and deserve. Examples include more in-home caregiver support and other benefits such as healthcare, disability compensation and pensions. We also pair patients with our active and retired military volunteers, to further assure that veterans receive the dedicated help they've earned.



**Primary Care at Home:** This newly launched program helps home-limited seniors safely age in place by managing serious chronic illness and avoiding 911 calls and hospitalizations. The innovative approach is currently available in the Northern Virginia, Northwest D.C., and Chevy Chase, MD, areas.



**Stay-at-Home Services:** Capital Caring Health knows that for most people 'there's no place like home'. Our Stay-at-Home Services was designed to provide that personalized, extra level of care to elders who value their independence yet need a helping hand in order to remain in their homes.

Stay-at-Home Services is essentially a one-stop shop for scheduling and managing a broad range of care and support needed to remain independent in the home.



**Patient Pet Services:** Capital Caring Health is committed to ensuring that patients have access to the care and support they need to remain in their homes, in comfort and with all those that they love. Volunteers play an important part in helping patients with home pet care. Specially trained dogs provide unconditional love and comfort to bereaved children, as well as adults who may have difficulty communicating due to illness or disability as part of our Pet Therapy program.



**Volunteers:** Started by volunteers, Capital Caring Health now counts on our 1,000 volunteers in many different ways:

- To provide comfort and companionship by reading to patients or running errands for stressed families
- To offer grief support over the phone, in the home, and through art and music therapy groups
- To help patients with home pet care and pet therapy



**Bereavement/Grief Support:** For a full year and beyond, Capital Caring Health's trained counselors offer comprehensive bereavement support to individuals and families who have suffered a loss for a full year and beyond, if needed. At regular check-ins, we'll remind you of available support—individual and family counseling and special services for children of all ages including pet therapy, camp with peers, a school-based program and more.

Our wide variety of support groups and workshops focus on moving through grief and healing with memorials, art, music and nature programs, peer support groups and in time, planning for a new life.

All bereavement programs and services are available at no cost to all members of the community, whether or not they used our services.



### *Other Services*

**Point of Hope:** CCH's unique counseling program offers support groups and workshops that meet the diverse needs of caregivers by covering topics such as caring for terminally ill parents or children to dealing with loss while caring for Alzheimer's and other dementia patients.

**Tuck-in Calls:** Two to three times each week, all patients and families can count on bedtime "tuck-in" calls to check on each patient's health status and make sure there are sufficient medications, equipment and other supplies.

**Inpatient Care:** With 57 beds in four different settings, CCH has the largest in-patient capacity of any other hospice in the mid-Atlantic, and continues to grow. Patients who require care that cannot be managed at home can stay in a home-like setting, receiving high-quality care around the clock; family, friends and pets are welcome at any time, day or night, with no restrictions on visitation.

## Transitioning to Hospice

**Knowing when your loved one will be admitted and receive timely palliative or end-of-life care is important.** A description of the referral process should be available on the hospice website including a toll-free number and online forms to submit.



**Note that not every hospice is staffed to admit or start care during weekday evenings, weekends, or holidays. While most hospices try to begin care within 48 hours, the time it takes to enroll in hospice and begin care varies.**

In the event of a medical crisis, every hospice should have a 24/7 Care Line to answer questions or get more help. Ask the hospice how they handle a medical crisis if it occurs at night or on the weekend and whether they will send medical staff to the home, if needed.

**Capital Caring Health is committed to providing timely care and support for you and your family.** We're available to process admissions and/or begin care anytime day or night, including weekends. And once you elect hospice, we usually begin care within 48 hours, starting with a discussion about a custom care plan with a hospice physician. Our immediate focus is management of pain and other symptoms. We are available 24/7 to answers questions and/or handle a patient medical crisis. If needed, a member of the clinical staff will visit the home including evenings and weekends.

**Before any care begins, you or your doctor will need to make a referral.** To get started, please call 800-869-2136 or fill out and submit the online information form (name, preferred contact and what service you are interested in).

## Peace of Mind

The healthcare decisions we make for ourselves and our family are important. This is especially true when it comes to choices for end-of-life care.

Hospice care offers comfort, peace of mind and quality of life for our loved one and family when it is most needed.

Our hope is that this guide and checklist has put you on the right track to make the best-informed decision for your loved one, now and in the future.



## About Capital Caring Health

**Capital Caring Health** is one of the leading nonprofit providers of elder health, hospice, and advanced illness care for persons of all ages in the mid-Atlantic region. Our mission is to provide patients and their families with advanced illness care that is second to none. We also have special hospice teams serving children and veterans and serve over 7,000 hospice patients each year. Our website, [capitalcaring.org](https://capitalcaring.org), is available in English, Spanish, and Korean plus offers 24/7 Live Chat. Since our founding over 40 years ago, we have served more than 120,000 patients and their families in Maryland, Virginia, and the District of Columbia.

## About NPHI

**The National Partnership for Hospice Innovation (NPHI)** is an organization comprised of 70 nonprofit hospice organizations, driven by passion and integrity to help people live fully through the end-of-life. Our most important ideas are learned at the bedside, not in the board room. Our members are patient, family and community-focused hospice, palliative care, and advanced illness providers across the country made up of like-minded leaders with expertise and passion for the highest quality, person and family-centered, mission-oriented end-of-life care. For the location of the nearest NPHI member hospice organization outside of the Capital Caring Health service area, call 1-844-GET NPHI (1- 844-438-6744).



Log on to [capitalcaring.org/hospice](https://capitalcaring.org/hospice)  
for additional resources and more information.

**24-hour Care Line: 800-869-2136**

