

Capital Caring Health

Advanced Home Care & Hospice for All Ages at All Times



No Place Like *Home*

Guide





Home. For most of us, it's central to our sense of wellbeing and belonging...of feeling safe and sound...of being comfortable and comforted. Yet age or advanced illness, disease or disability can threaten one's independence, quality of life...and ability to remain in their own home.

At any step along life's journey, at any age, Capital Caring Health can help keep you or your loved ones where they want to be.

Since 1977, we've relieved pain and suffering...resolved worries and concerns...and renewed spirits and peace of mind for hundreds of thousands of patients and families throughout Washington, D.C., Maryland and Virginia... all in the comfort of their own homes.

This Guide provides tips and resources to help you and your loved ones receive compassionate, personalized care on your terms and wherever you call home.

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. A member of a national network of more than 65 nonprofit hospice providers, 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. **On an annual basis we serve over 7,000 hospice patients and provide more than \$3 million in charity care to those who are uninsured and have nowhere else to turn. Almost 90 cents out of every dollar goes to caring for patients and their families.** Our website, capitalcaring.org is available in English, Spanish, and Korean plus offers 24/7 Live Chat. Since the beginning of hospice care over 40 years ago we have served 120,000 patients and their families in Maryland, Virginia, and the District of Columbia.



24-hour Care Line: 800-869-2136

capitalcaring.org



Hospice Care

TIP #1

Don't Wait Too Long to Ask for Help

For some people with an end-stage illness, treatments that used to keep disease under control simply stop working. Many patients and families then decide to discontinue curative therapies in favor of pain and symptom management only, and to focus their energies on what's most important during life's last phases.

Hospice can help you and your loved ones deal with the inevitable changes that occur and help you both live life to its fullest—most often in the comfort of your own home. In fact, while hospice care can be delivered anywhere—including senior living and skilled nursing facilities—more than 95 percent of patients receive care in the familiarity of their own home.

Through Capital Caring Health's hospice program, you'll have a full care team of doctors, nurses, aides, social workers, chaplains and volunteers, and 24/7 access to a healthcare professional to address any concerns. Specialists attend to you and your family's physical, emotional

and spiritual needs to create a comfortable, peaceful and dignified quality of life. Hospice patients also receive “tuck in” calls two to three times a week to inquire about a patient's health status, and ensure they have sufficient medications, equipment and supplies on hand. Furthermore, you may also ask your regular doctor or nurse practitioner to partner with us as your primary attending medical supervisor. The choice is yours. And, hospice is covered by Medicare, Medicaid and private insurance.





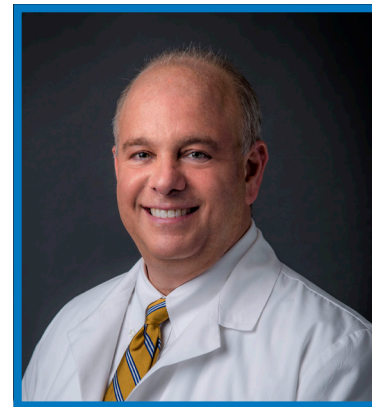
Hospice Care



Hospice is designed for those in the last six months of life, although care can be extended. Surveys show that patients and families derive the greatest benefit and highest satisfaction when a patient spends at least two to three months in hospice care, if not longer.

Ultimately, hospice is about life, and the team works to make each day as good as possible...for every patient and family in our care.

Many families tell us they wished they had contacted us sooner to help care for a loved one. When you think you or a loved one might benefit from hospice care, we have the detailed information and support you need. Once you choose to receive hospice services, care usually begins within 24 to 48 hours, starting with a discussion with a hospice team about a custom care plan for you.



Dr. Matthew Kestenbaum
Chief Medical Officer



Advanced Illness (Palliative) Care

TIP #2

Reduce the Symptoms and Stress of Serious Illness

Today's medical treatments can often ease or even cure serious illness. Yet sometimes those same treatments can also cause pain and other unpleasant side effects, adding to the stress of being sick. Just coping everyday with illness can also take a toll, as patients and caregivers alike struggle to remember multiple medications...juggle numerous doctors' appointments...and manage their own hopes and fears.

Capital Caring Health's advanced illness program (also called palliative care) offers specialized medical care that can help you live your fullest life possible, even as you deal with a serious condition. We focus on relieving the symptoms, pain, stress and other burdens of advanced illness, with the goal of improving quality of life for both you and your family.

Anyone suffering from a chronic, progressive disease can receive advanced illness care, at any point during treatment. That means we can help you get relief from your symptoms even while your

other physicians work to treat or cure your disease. And if your or your doctors decide that curative treatment is no longer effective, you can count on us to continue our care.

The service is available to all ages—from infants to the elderly—with such progressive, chronic diseases and conditions as:

- Cancer
- Dementia including Alzheimer's
- Heart disease
- Kidney disease
- Liver disease
- Lung disease
- Neurologic disease (ALS/Lou Gehrig's Disease, Parkinson's Disease, stroke)
- Birth defects
- Disabilities and health conditions from prematurity



Advanced Illness (Palliative) Care

Our advanced care specialists will work with your primary medical team to address your unique needs, and help improve symptoms related to serious illness and ease concerns such as:

- Pain
- Shortness of breath
- Fatigue
- Constipation
- Nausea
- Anxiety
- Loss of appetite
- Emotional distress affecting patients and/or families
- Confusion about what to expect in the weeks and months ahead
- Other needs

For the convenience of patients and family members, we deliver advanced illness care in many different settings including homes, hospitals, clinics, and long-term care facilities. In addition to expert symptom and pain management (see page 10), we can also help clarify your understanding of the illness and available options, assist in finding needed resources and other supplemental support and, if needed, help you transition to hospice care.





Primary Care at Home

TIP #3

Get the Right Care at the Right Time

Regular medical care is important throughout all of life's stages but is especially critical as we age. People over 65 often develop high blood pressure and heart disease, diabetes, severe arthritis and other chronic health issues. And some people suffer from a combination of ills. Without the right medical care to control your conditions, your health, quality of life and independence can quickly decline.

Yet if advanced illness, disability, or a simple lack of transportation makes getting out and about difficult, regular visits to your physician's office can seem overwhelming.

If that sounds familiar, Capital Caring Health's new Primary Care at Home (PCH) program may be just what the doctor ordered.

Through PCH, we bring the doctor to you. Our team provides person-centered primary and urgent care as well as social support to stabilize and maintain your health, control chronic conditions...and keep you at home. **Our comprehensive services include:**

- A dedicated, interdisciplinary care team to coordinate all the services you need from diagnosis to treatment to monitoring;
- 24/7 phone access for timely, efficient care;
- Intensive-level care in the home, through our advanced mobile technology;
- Care planning with you and your family members;





Primary Care at Home

- Coordination of hospital care and specialists;
- Counseling and training for family caregivers;
- Access to support services like home health aides, legal and financial resources, and crisis intervention;
- Health education on nutrition, exercise, and activities of daily living, based on your current state of health;
- When needed, a close link to Capital Caring Health's premium palliative care and hospice services.

PCH is designed and led by Eric De Jonge, M.D., one of the nation's most renowned geriatricians, who helped pioneer the concept of home-based primary care for elders more than 20 years ago. Through our effective and affordable program, we help you avoid unnecessary 911 calls and often costly emergency room visits or hospital stays that can add to your stress and anxiety. And ultimately, we hope to improve your ability to live life to its fullest—with health, dignity and independence—and provide peace of mind for you and family members.

Primary Care at Home services is currently available in Chevy Chase, Maryland; Northwest, D.C.; and Fairfax/Arlington, Virginia. Additional neighborhoods will be added at a future date.

For more information, see *Coping with Illness*, *Taking Care of Elderly Patients*, *How to Talk to Your Parent's Doctor*, *Primary Care at Home* and other helpful guides under "Resources" on our website, www.capitalcaring.org

For information regarding Primary Care at Home in Northern Virginia, call (703) 333-6969

For information regarding Primary Care at Home in DC/Chevy Chase, call (202) 844-4922



Dr. Eric De Jonge
Chief of Geriatric Services



Stay-at-Home Services

(available in January 2020)

TIP #4

Don't Sweat the Small Stuff

Sometimes, we all could use a little help in navigating our daily lives. But if you are recovering from an illness or medical procedure—or are home-limited due to a chronic disease or disability—the list of what assistance and services you need may be quite a bit longer.

Help is on the way.

Through Capital Caring Health's new Stay-at-Home Services—a complement to our Primary Care at Home program—a full array of supplemental offerings will soon be at your fingertips. **Through this service, friendly care coordinators will help arrange many types of in-home assistance you may need, including:**



It's all part of our vision to create a “one-stop-shop” for elders, combining support for activities of daily living and other tasks with ongoing access to medical care, all in the comfort of home. The bottom line is enhanced convenience, safety and dignity for the home-limited elders in our care, as well as peace of mind for their families.

So, if you need it, chances are we can arrange it. Just ask.



Pain Management

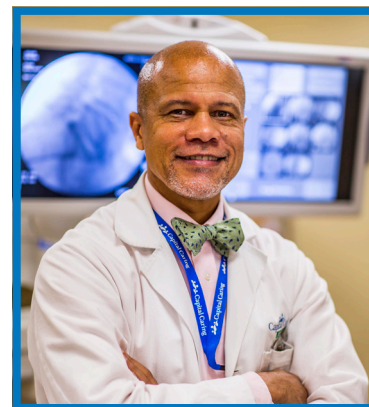
TIP #5

Put Pain in Its Place

Aches and pains. Even if you're relatively healthy, these common complaints just seem to go with the territory as the years go by. But a serious, progressive disease or disability can contribute to and even magnify your pain, eroding your quality of life—at any age.

Unfortunately, pain is part of many life-limiting illnesses, and can even be an unintended consequence of treatment. Yet that doesn't mean you or loved ones must live with it.

As a leader in pain management, Capital Caring Health has helped thousands of area residents over the years, with the majority of care provided successfully at home. Following dedicated clinical protocols for the best outcomes, we use a comprehensive, interventional approach to relieve pain, discomfort and other symptoms of advanced illness. Our goal is to reduce pain to a manageable 0–2 level on a 10–point scale within the first 48 hours, which has the added benefit of reducing your stress and anxiety. You shouldn't have to wait for pain relief care.



Dr. Bias-Smith
*Medical Director, Adler Center for
Interventional Pain Management*



Pain Management

Sometimes, however, more intense pain or symptoms may require more intensive care. For those patients, our Center for Pain and Palliative Care is the answer. The only clinic of its kind in the region, the center provides outpatient care at two locations: the Capital Caring Adler Center on the Van Metre Campus in Virginia and at the District of Columbia's Sibley Memorial Hospital, affiliated with Johns Hopkins. **Both sites provide precision diagnosis and targeted intervention for the most advanced pain management, including:**

- Lymphedema therapy (for swelling of the arms or legs after some cancer treatments)
- Neurolytic procedures (a type of nerve block)
- Sympathetic nerve blocks
- Intrathecal pump therapies (an implanted pump that delivers medication directly to the spinal cord)
- Epidural and major joint injections
- Injections for axial spine fractures
- Ascites and pleural effusion management (treats fluid build-up from cancer that may accumulate in the lungs, chest cavity and abdomen)

Of course, not all pain is physical. For people with life-limiting conditions, emotional and spiritual pain is just as real, and often makes bodily pain even worse. See page 5 to learn more about our palliative care program overall, and page 16 for the many types of counseling and family support we offer.





Veteran's Health and Support Services

TIP #6

Understand and Take Advantage of Your Military Benefits

If you're a veteran with a chronic or life-limiting health problem, the last thing you need is the added burden of navigating the complicated VA system. Yet that's often the fate awaiting many of those who served, as we've learned over decades of caring for veterans.

When they most need help, ailing and aging veterans far too often run into problems securing the health and welfare services and benefits they've earned. Capital Caring Health has expanded our existing care and advocacy program for vets and devoted additional resources to create a new program dedicated to Veteran's Health and Support Services. This program focuses on assisting veterans with what they need the most—unlocking the doors to multiple VA benefits and entitlements that can improve their lives.

By working directly with state-level Veterans Affairs offices, accredited agencies and established

veteran's organizations, **Capital Caring Health can help veterans throughout Virginia, Maryland, and Washington, D.C., with:**

- Enrolling in the VA healthcare system;
- Obtaining an accurate diagnosis for service-related conditions;
- Determining eligibility for disability compensation and pensions;
- Receiving in-home caregiver support and other services;
- Gaining access to additional resources for help with everyday challenges, such as transportation, home maintenance, pet therapy, and more.



Veteran's Health and Support Services

We also provide a full range of services for those with life-limiting illness including medical and psychological care for issues common to veterans. Care is provided wherever you live, from a senior living facility to a VA nursing home unit, to your own home. We also match our veteran patients with other veterans or active duty military volunteers to provide companionship and serve as champions to make veterans feel heard and understood.

Altogether, our goal is to offer “boots-on-the-ground” assistance that makes a difference in the quality of life for our veteran patients.

Call our 24-hour Care Line at (800) 869-2136 to ask questions or schedule a consultation.



Lt. Col. (ret) David Benhoff
*Director of Veteran's
Health & Support Service*



Children's Hospice and Palliative Care

TIP #7

Receive Specialized, Compassionate Care for Your Sick Child

Learning that your child is disabled, or has a life-limiting, chronic disease is possibly the worst moment in any parent's life. Your natural instinct is to protect and defend your child, yet in this situation, you're seemingly helpless to do anything. It's unfair and offends our sense of what's right and good in the world.

At Capital Caring Health, we understand. Since first opening our doors, the care of sick infants, children, and adolescents has been a cornerstone of our foundation. In fact, we are one of the oldest and largest providers of pediatric palliative and hospice care in the nation. Our own expertise is enhanced by partnering with Children's National Hospital—one of the country's leading pediatric hospitals—for virtual consultations, and through additional support from pediatric palliative care physicians from INOVA Fairfax Hospital.

Altogether, we offer both advanced illness (palliative care) and hospice care for any child of any age, with

services almost always provided in the comfort, privacy, and convenience of your own home. Even

as we work to manage pain and other symptoms, your child may continue to receive treatments designed to improve or cure his or her condition, as well as home health and specialized nursing care from other providers. If intensive symptom management is needed, Capital Caring Health has four specialized inpatient facilities which have accommodations for overnight family stays. Visitors are always welcome.

In addition to physical care, we also offer emotional, spiritual and other support services to help a child and family cope. Chief among those is assistance in sorting through tough decisions about services and treatments for your child, and their impact on quality of life, consistent with your family's values.



Tara Hoit
Director of Children's Programs



Children's Hospice and Palliative Care

Services include:

- Consultation with our board-certified physician/nurse practitioners in coordination with the child's physicians and other health care providers.
- Nurse visits to manage pain and other symptoms.
- 24/7 support for questions and nursing visits.
- Home delivery of medications and equipment.
- Hospice home health aides to assist with daily care needs.
- Social workers to help children and families cope with both emotional and practical issues.
- Grief counselors to guide families through grief and loss.
- Child and Family Clinical Specialists to help the whole family express what they're feeling.
- Chaplains for spiritual and pastoral support.
- Specially trained volunteers to assist the child and family.
- Periodic respite care at one of our inpatient care centers when family caregivers are unavailable or unable to provide patient care.

In short, we are dedicated to helping children, siblings and parents with holistic, family-centered care, day in and day out. With compassion, insight, expert medical care and emotional and spiritual support services, our focus is always on the health and wellbeing of your child, and your family's quality of life, as you define it.

If you think your child might benefit from our specialized care, please call us at 800-869-2136. We can help you move through every step of the process and get your child and family the care and support you need.

Support for the Grieving Child

Sometimes children need care, and other times children need solace...particularly when they are trying to come to grips with the death of a loved one. Capital Caring Health offers a wide range of programs and activities to help children of every age deal with their grief—by talking with our trained counselors, spending time with other children in a similar situation, and experiencing the fun and distraction of day camp, art, music and pet therapy. Services are available to any child in our community, at no charge. For more details, please see page 16.



Grief Support

TIP #8

Let Us Help Share the Burden

There comes a time in everyone's life when we must say goodbye to someone we love. Whether it's the slow decline of a parent...the sudden loss of a spouse or child...or your own mortality in the face of end-stage disease, you don't have to go it alone. Capital Caring Health is here to help with expert and compassionate counseling and grief support.

Since each of us experiences loss in his or her own way, we have a wide array of options tailored for people of all ages, from kids to adults. **Through one-on-one, family, or peer group sessions, our highly qualified staff offers:**



Marcie Fairbanks
Director of Family Services

 Telephone support	 Short-term individual and family counseling	 Pastoral counseling
 Pet care	   Support groups/workshops for all ages that include music and art therapy, nature walks, and more.	



Grief Support

Children and teens may have an especially difficult time expressing and processing their grief, requiring special approaches. We bring together other bereaved kids of the same age for group activities and conversation in school or camp settings. Individual counseling is also available. All programs are available to any child in our community, at no charge.

Capital Caring Health also offers an extensive schedule of support groups and workshops that provide something for everyone coping with grief and loss. From meetings set in nature to using music, art, or books to find meaning in life during trying times, we can help you and your family find comfort and relief when you need it most.

We cover many topics related to dealing with advanced illness or disability as well as the loss of a loved one, including:

- You and Your Aging Parent;
- Loss of Control;
- Loss of Mobility;
- Loss of a Spouse or Life Partner;
- Loss of a Child;
- Loss of a Sibling;

- Managing the Day-To-Day Impact of Your Disease;
- Staying Connected with Loved Ones;
- Making Peace with Loved Ones;
- Spiritual Questions;
- Dealing with Grief during the holidays.

Life can be challenging, but with Capital Caring Health in your community, you have a compassionate and expert resource to turn to. Let us help.

To view a schedule of support groups and workshops offered in your community, please see our online Monthly Calendar. *To learn more about our counseling services and make an appointment, please contact (800) 869-2136.*





Stay Informed

TIP #9

Stay Informed

With healthcare as with anything else in life, it's hard to make a good decision if you don't have the right answers. From understanding your disease to knowing your options, the most informed patients are the most satisfied, especially when it comes to care choices during the latter stages of life.

Here are some of the most common questions we receive:

Who's eligible for Advanced Illness and Hospice Care?

Anyone who has a serious progressive disease, life-limiting condition or life-expectancy of less than six months is eligible for advanced illness (palliative care) or, in the case of the latter, hospice care. Common conditions include cancer, Alzheimer's and other forms of dementia, heart disease including congestive heart failure, stroke and other neurological conditions, lung disease such as COPD, liver disease and more. Capital Caring Health's representatives can help you determine your eligibility any time of the day or night.

How will I know it's time for Advanced Illness or Hospice Care?

As certain conditions progress, you may need advanced illness/palliative care or hospice care to control symptoms—including pain—to assure quality of life for both you and your family. We have condition-specific information online, (<https://www.capitalcaring.org/resource-center/condition-information/>) with descriptions of when you might want to contact Capital Caring Health for guidance, but general warning signs include:

- Pain
- Shortness of breath
- Fatigue
- Constipation
- Nausea
- Anxiety
- Loss of appetite
- Emotional distress
- Confusion

Start by talking to your doctor or your family member's physician about your concerns and whether it's time to explore additional options. Our experts can also help you and your family decide what's right for you, and when.



Stay Informed

What's the difference between Advanced Illness and Hospice Care?

Palliative care services may begin at any time during an illness, even while the patient continues to receive curative treatment from their physician. To discuss or start care, please call us or, fill out an online form at <https://www.capitalcaring.org/start-care/>.

To access hospice care, your physician and the medical director of a hospice must agree that you have a life expectancy of six months or less. You must also be willing to stop curative care.

Who pays for care?

Advanced illness and hospice care are covered by Medicare (if you are over 65 or eligible for Medicare due to disability). Hospice services are typically covered 100 percent, with limited, small copayments. Medicaid and private insurance coverage generally cover adult and pediatric services with limited out-of-pocket costs. Check with your employer or health plan for specific coverage details.

If you have no coverage or insufficient funds, our Patient Care Fund may be able to provide financial assistance. No one is ever turned away because they can't pay. A Capital Caring Health Care Navigator

can help you determine your coverage and provide help should you need to apply for benefits. For more information, visit www.capitalcaring.org/resource-center/financial-information/cost-of-care/.

Grief counseling services and support groups and workshops are available to members of the communities we serve, at no charge.

How do I arrange a referral for Capital Caring Health services?

You can directly arrange a referral, or your attending physician may do so. For direct help, call us or, fill out our online form at <https://www.capitalcaring.org/resource-center/navigating-care/applying-for-care/>.

How do I sign up for Primary Care at Home?

This new program launches December 2019 in select areas of Chevy Chase, Maryland, NW Washington, D.C., and Falls Church, Virginia. Visit www.capitalcaring.org/pch for the zip codes where care is being provided. Additional neighborhoods will be added as the program grows. The program is open to those 65 and over, with a serious illness and physical or cognitive disability.



Contact Us

TIP #10

We're Always Open and Ready to Help

For more than 40 years, Capital Caring Health has provided holistic, person-and family-centered care to area residents with life-limiting progressive illnesses, disabilities and disease. We can help you, too.

Founded in 1977, we are one of the nation's oldest and largest nonprofit providers of hospice and palliative care, improving quality of life for more than 120,000 patients and their families over the years. Each day, more than 800 employees and 1,000 volunteers provide services to nearly 1,300 patients throughout the District of Columbia, Maryland's Prince George's and Montgomery counties, and from Northern Virginia to Fredericksburg and Richmond. In the vast majority of cases, we deliver care directly to you, in your own home.

We also offer inpatient services when patients need more intensive care, or when caregivers are unavailable or unable to provide the care required. In fact, we have the greatest inpatient capacity of any other hospice in the region, with 57 beds within our four facilities. Additional Capital Caring Health beds are also available at area hospitals. A new inpatient facility will open at Sibley Hospital in Washington, D.C., in early 2020 in partnership with the Washington Home.

As a nonprofit, we're also mission-driven, assuring that no one is ever turned away for lack of funds. Thanks to donor support, Capital Caring Health contributes approximately \$3 million of charitable services to members of our community who need our special combination of compassion, care and support—each and every year. And, 90 cents of every dollar goes directly to patient and family care.

Our longevity and expertise, along with our history of public education and advocacy, have made us leaders in the field, with Capital Caring Health's specialists contributing new ways of thinking about health, aging and life-limiting conditions. As a founding member of the National Partnership for Hospice Innovation (NPHI)—a network of more than 65 nonprofit hospice organizations—we are continually evaluating innovative methods to allow patients of all ages and their families to remain in the comfort of their own homes, always with a focus on quality of life.

Find out how we can help you and your loved ones make the most of every moment and live the best life possible. For more information, contact us 24/7 at 1-800-869-2136, or visit www.capitalcaring.org.

Our Locations

Falls Church, Virginia

Capital Caring Headquarters

3180 Fairview Park Drive
Falls Church, VA 22042
703-538-2065

Richmond, Virginia

9020 Stony Point Parkway
Suite 170
Richmond, VA 23235
804-601-3180

Aldie, Virginia

*Capital Caring Adler Center on the
Van Metre Campus (inpatient unit)*

24419 Millstream Drive
Aldie, VA 20105
703-957-1777

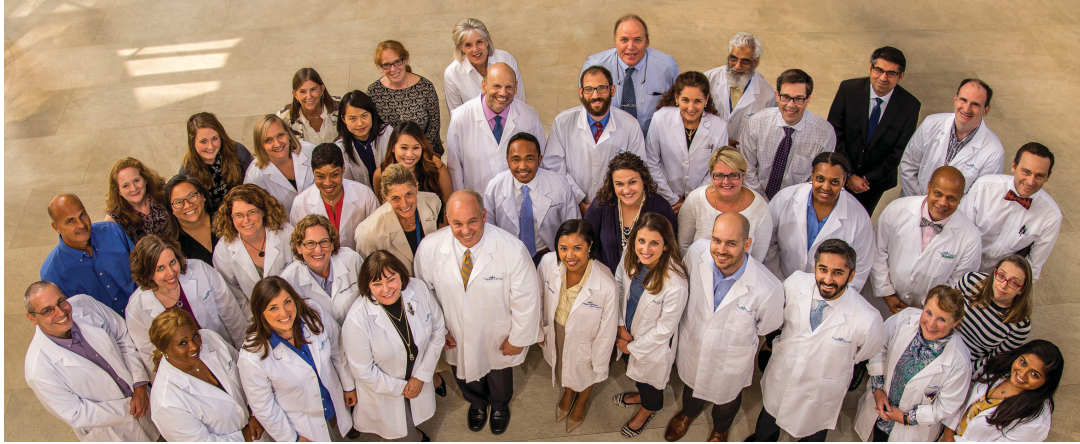
Richmond, Virginia

Palliative Clinic

Virginia Cancer Institute
at the Sara Cannon Building
1401 Johnston Willis Drive, Suite 100
Richmond, VA 23235

Alexandria, Virginia

5845 Richmond Highway, Suite 150
Alexandria, VA 22303
703-333-6960



Largo, Maryland

1801 McCormick Drive, Suite 180
Largo, MD 20774
301-883-0866

Arlington, Virginia

2900 Telestar Court
Falls Church, VA 22042
703-538-2065

Greenbelt, MD

*Capital Caring Center Prince
George's County Maryland*
9885 Greenbelt Road, 3rd Floor
Lanham, MD 20706
301-850-5468

Arlington, Virginia

*Capital Caring Halquist Center
(Inpatient unit)*
4715 North 15th Street
Arlington, VA 22205
703-908-5900

Washington, DC

50 F Street, NW, Suite 3300
Washington, DC 20001
202-244-8300

Fredericksburg, Virginia

111 Olde Greenwich Drive
Fredericksburg, VA 22408
540-891-1200

Washington, DC

*Capital Caring Center at
Providence Hospital (inpatient unit)*
2nd Floor, 2 South
1150 Varum Street, NE
Washington, DC 20017
202-844-4920

Fredericksburg, Virginia

Palliative Clinic

4600 Spotsylvania Pkwy, Suite 300
Fredericksburg, VA 22408

Washington, DC

*Capital Caring Center at Sibley
Hospital (Palliative Pain clinic)*
Sibley Medical Building A
5215 Loughboro Road NW
Suite 460
Washington, DC 20016
202-327-8294



Hospice | Advanced Illness Care | Elder Health | Children's Hospice & Palliative Care
Veteran's Health & Support Services | Grief Support | Patient Pet Services