

*Patient & Family*

# GUIDE TO HOSPICE CARE AT HOME





## WELCOME

On behalf of the Capital Caring Health team, our Board of Directors, and Volunteers, I would like to thank you for the opportunity to provide care and support at this important time.

Since the beginning of the hospice movement almost 50 years ago, Capital Caring Health has been the region's nonprofit, community-based advanced illness care provider. Since our inception in 1977, we have not only provided comfort and care to the Washington Metropolitan Region, but we have also paved the way as a national leader in the hospice movement.

Capital Caring Health is grounded in our mission of providing patients and their families with advanced illness care of the highest quality and being the best place to work in healthcare.

Through our commitment to our core values of putting patients and families first, always doing the right thing, and respecting everyone, we always focus on providing exceptional care. We are also proud of the comprehensive range and services we have developed to address a wide range of needs from counseling, palliative care, respite, specialized resources for Veterans, and more.

There are many helpful resources in this guide as well as on our website, [capitalcaring.org](http://capitalcaring.org), to assist you on this journey. Our experts are also always available on our 24-hour care line at (888) 325-1239. Please let us know how we can help!

The satisfaction of the patients, caregivers, and families we serve is our highest priority. You may also reach me directly with questions or feedback at [communications@capitalcaring.org](mailto:communications@capitalcaring.org).

Thank you again for the opportunity to support you during this journey. We are grateful for the chance to show you the difference Capital Caring Health can make to empower patients, ease caregiver burdens, and help improve quality-of-life.

Regards,

Kimberly Grove, Managing Director





**See Page 3** for  
How to contact  
Capital Caring  
Health

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ABOUT CAPITAL  
CARING HEALTH  
HOSPICE  
SERVICES



# 1 ABOUT CAPITAL CARING HEALTH HOSPICE SERVICES

## *Our mission*

Provide Patients and their Families with Advanced Illness Care of the Highest Quality.

## *Our commitment*

**TO THE PEOPLE WE SERVE:** Our family-centered approach responds to your physical, emotional and spiritual needs. Care is provided regardless of ability to pay.

**TO OUR PARTNERS IN CARE:** We provide ease of referral; timely and appropriate communication. We value our cooperative alliance in meeting patient and family needs.

**TO OUR STAFF AND VOLUNTEERS:** We maintain a supportive work environment that fosters enthusiasm, teamwork, respect and growth.

**TO THE COMMUNITY:** We recognize our unique partnership in this work. We provide quality services and education for patients and families living with advanced illness. We are responsible stewards of our resources.

## *What is hospice?*

Hospice provides physical, spiritual and emotional care to people who are nearing the end of life. Hospice focuses on providing comfort and quality of life tailored to the patients' needs and wishes. Support is provided to the patient's loved ones as well.

## *Your hospice team*

Capital Caring Health provides hospice services and offers you an expert team of professionals and volunteers to help develop a plan of care to meet your individual needs and the needs of your family/caregivers. Together, we will create a plan of care based on your goals and the services needed to maintain your comfort and manage your illness either in your home or in a facility. Based on your specific needs, your team may include:

**YOUR PRIMARY PHYSICIAN, A NURSE PRACTITIONER AND A HOSPICE MEDICAL DIRECTOR** will work together to coordinate your care.

**A REGISTERED NURSE CASE MANAGER** will manage and coordinate your plan of care and the team's services according to the physician's orders. The nurses will teach you and your caregivers many of the skills and information discussed in this training guide.

Any question,  
day or night,  
**888.325.1239**  
We are here  
for you.



A **HOSPICE AIDE** will help provide your personal care such as bathing, skin care and linen changes, which are planned and approved by the nurse based on a discussion with you regarding your needs. He or she will report any significant changes in your condition to the appropriate team members.

*Hospice Aides cannot:*

- Administer medication
- Change oxygen settings
- Suction secretions
- Administer a feeding tube
- Perform full housekeeping duties
- Transport to/from appointments

A **SOCIAL WORKER** will help support you with things such as:

- Communication
- Referrals to community resources
- Emotional support, counseling, coping strategies
- Assistance with finances
- Advance Care Planning

A **SPIRITUAL CARE ADVISOR** (interfaith chaplain) will assist you or your family with spiritual needs and requests. This includes discussions and activities focused on what brings joy and meaning into life as well as requests for religious support from community clergy of your choice. Many patients and families find this support very helpful as significant spiritual issues often arise due to serious illness.

A **BEREAVEMENT COORDINATOR** supports you and your loved ones. Bereavement support is offered for 13 months following the loss of a loved one.

**VOLUNTEERS** are available to provide support and companionship to you and your family/caregiver. They may provide companionship when your caregiver needs to run errands or keep an appointment, can assist with transportation, shopping or light housekeeping.

*Volunteers cannot:*

- Provide personal care
- Manage medical equipment
- Administer medications
- Other services such as physical therapy, speech therapy or nutrition services.



# LOCATIONS AND SERVICE AREA

## VIRGINIA

### FAIRVIEW PARK REGIONAL OFFICE

3180 Fairview Park Drive, Suite 500  
Falls Church, VA 22042  
*(Serves Arlington County, Fairfax County, and the independent cities of Alexandria, Fairfax, and Falls Church)*

### HEADQUARTERS

3180 Fairview Park Drive, Suite 500  
Falls Church, VA 22042

### ADLER CENTER FOR CARING ON THE VAN METRE CAMPUS INPATIENT CENTER

24419 Millstream Drive  
Aldie, VA 20105

### ADLER REGIONAL OFFICE

24419 Millstream Drive (lower level in the back of the building)  
Aldie, VA 20105  
*(Serves Loudoun County, Prince William County, Fauquier County, and the independent cities of Manassas and Manassas Park)*

## DISTRICT OF COLUMBIA

### DC REGIONAL OFFICE

5225 Wisconsin Ave, NW, Suite 503  
Washington, DC 20015  
*(Serves all 8 Wards)*

### THE WASHINGTON HOME CAPITAL CARING HEALTH INPATIENT CENTER

Sibley Memorial Hospital Building C  
5255 Loughboro Road NW, 5th Floor  
Washington, DC 20016

## MARYLAND

### MARYLAND REGIONAL OFFICE

9885 Greenbelt Road, Suite 300  
Lanham, MD 20706  
*(Serves Howard County, Prince George's County, and Montgomery County)*

To speak with the  
Capital Caring Health Team  
call the 24-Hour Care Line:  
**(888) 325-1239**

# HOW TO CONTACT CAPITAL CARING HEALTH

## NAMES OF YOUR CARE TEAM

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Nurse

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Personal Physician

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Capital Caring Health Hospice Physician

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Nurse Aide

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Spiritual Care Advisor

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Social Worker

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Volunteer

## COMPLIMENTS OR CONCERNS

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Clinical Supervisor

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Executive Director

Insurance coverage questions  
[703-531-6080](tel:703-531-6080)

Vice President, Organizational Performance  
[703-712-4874](tel:703-712-4874)

Community Healthcare Accreditation Program (CHAP)  
[1-800-656-9656](tel:1-800-656-9656)



*Dr. Josefina Magno, founded Capital Caring Health (formerly known as Hospice of Northern Virginia) in 1977.*

## Capital Caring Health Hospice Services

Capital Caring Health provides care for individuals with serious advanced illness in our community regardless of race, color, religion, age, gender identity, sexual orientation, national origin or ability to pay. We acknowledge and appreciate the diversity of the people we serve, and our team members represent that same rich diversity. Therefore, all staff assignments are made without regard to race, color, religion, age, gender, sexual orientation, or national origin. In addition, we assist people during life transitions and traumatic events and believe the care of those living with advanced illness can, and should, be improved locally, regionally and nationally.

We are one of the largest and oldest hospices in the nation, founded by an insightful and pioneering physician, Dr. Josefina Magno. Our founding hospices include Hospice of Northern Virginia (1977), Hospice Care of DC (1978) and Hospice of Prince George’s County (1982).

We are a complete hospice and palliative care provider, which means we offer home care, pain and symptom management, crisis care, and bereavement support.

We operate several inpatient centers to provide short term, acute care to manage symptoms or to provide caregiver respite care.

### INPATIENT CENTERS

- Capital Caring Adler Center on the Van Metre Campus | Aldie, VA  
[703-957-1777](tel:703-957-1777)
- The Washington Home Capital Caring Health Inpatient Center | Washington, DC  
[202-327-8262](tel:202-327-8262)

We care for nearly 1,200 patients and families each day, having served more than 120,000 patients & families for more than 40 years.

We have more than 1,000 specially trained volunteers and train new hospice, palliative care physicians and nurses through our partnerships with medical and nursing schools.

Medications, medical supplies and equipment **related to your illness and plan of care are provided by hospice. All necessary medications, supplies, equipment or services **must be approved and coordinated with the hospice team.****

# Payment for hospice services

Capital Caring Health offers four (4) levels of care as required under the Medicare Hospice Benefit. Each level must be deemed necessary and ordered by the physicians as part of your plan of care.

**ROUTINE HOME CARE** is intermittent care provided at your residence, in a skilled nursing facility, or another setting you consider “home.”

**CRISIS CARE** is provided in your home on a short term, time limited basis when the physician and care team determine you need extra support to manage complicated medical symptoms.

**INPATIENT RESPITE CARE** is coordinated, short-term care (five days or less) provided at a contracted facility.

**GENERAL INPATIENT CARE** is coordinated care provided at one of our inpatient centers or a contracted facility on a short term, time limited basis when the physician and care team determine you need extra support to manage complicated medical symptoms.

Capital Caring Health provides care for all in need, regardless of payment source. Generous community support enables us to help those who have insufficient payment resources. For more information about our programs and services, please visit our website at [www.capitalcaring.org](http://www.capitalcaring.org) or call us toll-free at 1-888-325-1239.

# Transfer or discharge from hospice care

Hospice care provides continuity of care and ongoing support services. If you move to a location outside our service area or choose to receive service from another health care provider, we will assist in collaborating with the new provider regarding information about your care. Depending on your insurance, if you transfer to another certified hospice program; we will request you complete required forms and will provide the hospice with information to complete the transfer.

**YOU ALWAYS HAVE THE RIGHT TO STOP HOSPICE CARE AT ANY TIME FOR ANY REASON.** If you decide that you no longer wish to receive hospice care, you will be asked to sign a required form; we are not allowed to accept this decision verbally. If you choose to stop your hospice care, you will go back to any Medicare coverage you had before you chose a hospice program. If you stop hospice care during one benefit period, any days left in that period are lost. However, you will still be eligible for hospice starting the next benefit period.

## DISCHARGE FROM HOSPICE CARE WILL RESULT WHEN

- You can no longer be certified as terminally ill with a prognosis of 6 months or less; we will have this conversation with you in advance of the discharge date as well as provide you with written information regarding this decision.
- You are admitted to a non-contracted facility.
- You do not adhere to a medication management or other behavioral contract.
- We determine there is a risk to our staff’s safety.
- You move out of our service area.
- You choose to transfer to another hospice.
- You choose to stop receiving hospice care.

# Advance directives

As an adult, you have the right to make decisions related to your own medical treatment both now and in the future. Your physician and other healthcare providers must tell you about any procedure or treatment, its benefits or effects and any predictable pain, complications or risks. What would happen if you could not make those choices for yourself because of injury or illness? Who would make those decisions for you?

## WHAT IS AN ADVANCE DIRECTIVE?

An advance directive is a document in which you state your healthcare wishes if you cannot make your own medical decision in the future. There are two (2) kinds of advance directives:

- A living will, in which you state in writing what kind of medical care you do or do not want if you become unable to make treatment decisions.
- A durable power of attorney (POA) for healthcare, in which you appoint a person to make decisions for you about your medical care should you become unable to do so.

**You can combine these two types of advance directives into one document.**

Capital Caring Health will honor your wishes regarding your medical care to the best of our abilities that fall within the scope of the law and within our available resources. If we cannot honor your wishes, we will try to transfer you to an agreeable healthcare setting.

## FREQUENTLY ASKED QUESTIONS ABOUT ADVANCE DIRECTIVES

### 1. HOW CAN I BECOME INVOLVED IN DECISIONS ABOUT MY MEDICAL CARE?

- Talk with family, friends, physician, nurse or social worker about your decisions.
- Ask questions and share your wishes with those involved in your care.
- Write your decisions in an advance directive and have witnesses sign the document.

### 2. WHO DECIDES WHEN I AM UNABLE TO MAKE TREATMENT DECISIONS?

By law, you are assumed to be able to make treatment decisions unless two (2) physicians agree you are not able to understand those decisions.

### 3. WHO WILL MAKE TREATMENT DECISIONS FOR ME?

If you do not appoint someone or leave specific instructions, the law allows your relatives to make decisions for you.

### 4. WHO MUST FOLLOW WHAT I SAY IN MY ADVANCE DIRECTIVE?

If your wishes are legal, anyone involved in your care must follow your wishes or try to find someone who will follow them.

### 5. WHAT IF MY PHYSICIAN AND I DO NOT AGREE ABOUT MY CARE?

We encourage you to communicate directly and openly about your choices. If you do not agree with the care plan presented to you, you have the right to seek other medical opinions.

### 6. WHAT SHOULD I SAY IN MY ADVANCE DIRECTIVE?

It is best to appoint someone who you trust will speak for you and to discuss the following questions with that person:

- Do you want treatment to try to restart your heart or breathing (CPR)?
- Do you want to be placed on a breathing machine if you cannot breathe on your own?
- Do you want to be fed by tubes if you cannot eat or drink on your own?
- Do you want to be kept as comfortable and free of pain as possible, even if that care shortens your life?

### 7. DO I NEED AN ADVANCE DIRECTIVE?

No, but it is wise to have one so that those who care for you know what you want should you become unable to make treatment decisions for yourself.

### 8. WHAT SHOULD I DO WITH MY ADVANCE DIRECTIVE?

Give a copy to the person you appoint to make treatment decisions for you, along with your physician, your family and anyone else who might be involved in your healthcare.

*Capital Caring Health has the following policies regarding Advance Directives and Living Wills:*

- We will place a copy of your advance directive or living will in your medical record.
- Your care will not be affected in any way if you choose to not have an advanced directive or living will.
- You may create, change or cancel an advance directive or living will at **ANY TIME** during your care.
- If you are unable to make decisions about your care and have not selected someone to your behalf, we will try to learn what your wishes would have been. We will assist family members who have the legal right to make those decisions under the law.

## *Do not resuscitate (DNR)/allow natural death (AND) orders*

When you are admitted to Capital Caring Health, your nurse and/or social worker will discuss your wishes regarding CPR in the event your heart and breathing stop. You may change your mind at any time.

**If you decide you DO NOT want CPR, your nurse or social worker will call your physician to discuss with him or her, obtain an order to place in your medical record and provide you with a form to complete. This form will also be given to you to keep in a safe and visible place in your home such as the refrigerator or bedroom wall. It should be taken with you if you call 911 or are admitted to a hospital. If this form is not seen by the rescue squad or other healthcare providers and your heart or breathing stops, they are required by law to try to restart your heart and breathing.**

**If you choose to have CPR in the event your breathing or heart stops, we will honor those wishes by calling 911 if you are a patient in our Virginia service area or by initiating CPR and calling 911 if you are a patient in our Maryland or DC service areas.**

## *The national POLST paradigm program*

The National POLST Paradigm helps you work with your hospice team so that you receive the medical treatments that are right for you and avoid medical treatments that you no longer wish to receive. POLST stands for Physician Orders for Life-Sustaining Treatment and it provides a way for you to express end-of-life treatment wishes such as whether you would want:

1. Emergency personnel to attempt cardiopulmonary resuscitation (CPR) in the event that you were found unconscious, not breathing, or without a pulse.

2. To go to the hospital, to be put on a breathing machine (if necessary), or if you want to be made comfortable where you are.

- After a discussion about your specific goals, your social worker will ask you about your interest in completing a form to document those goals. Completion of the form is always voluntary.

- Nationally known as a “POLST” form, each state has its own version and may choose a different name. For example:

**VIRGINIA: POST (Physician Orders for Scope of Treatment)**

**MARYLAND: MOLST (Medical Orders for Life Sustaining Treatment)**

**DISTRICT OF COLUMBIA: MOST (Medical Orders for Scope of Treatment)**

- After your form is completed, it is signed by one of our doctors, nurse practitioners, or physician assistants. This turns your wishes and goals into actual medical orders.
- Your form is placed on your refrigerator or bedside table, and a copy is placed in our hospice medical record.
- Please ask your social worker for more information about the benefits of having a POST/MOLST/MOST form.

# NOTES

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# PAIN CONTROL





## 2 PAIN CONTROL

The goal of hospice care is to achieve the best quality of life for the patient and their families. The control of pain is very important to your hospice care team.

### *About pain*

Pain is defined as an unpleasant sensory experience that serves as a warning that the body needs attention. There are many ways to manage all types of pain.

Every patient is asked about pain at the start of care and during every visit. We will ask you to rate the pain level and describe the pain you are experiencing. Sometimes patients and families assume we can tell when pain occurs, but this is not always true. Only you know when you are in pain, how bad it is, and what it feels like.

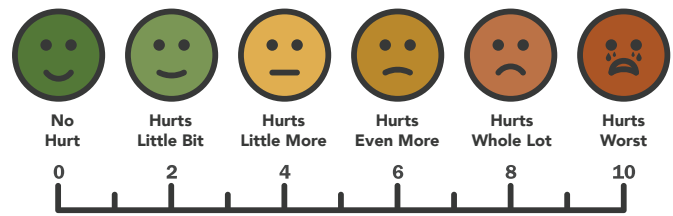
When you tell us about your pain you help us do a better job. You are not bothering us- you are a partner in your care.

### *Describing your pain*

It is important that you learn to describe your pain level, so you can report changes to us. Capital Caring Health measures pain on a scale of “0 to 10” with “0” being without any pain and 10 being the worst pain possible.

It is also important to tell us the location of your pain or discomfort when it occurs and how long it lasts.

### WONG-BAKER FACES® PAIN RATING SCALE





## *Frequently asked questions about pain management*

### **Q: I AM AFRAID I WILL GET ADDICTED TO THE PAIN MEDICINE**

There is very little risk for addiction to pain medicine when it is used correctly. When most think of addiction, they think of people who take a drug to “get high” or escape from life. Patients who take pain medication that is managed properly are instead trying to gain more out of life. Good pain relief offers better rest and more energy to be with family. When you take your pain medications as prescribed, you are using them correctly and legally. If your pain goes away, your team may be able to gradually and safely decrease the pain medicine.

### **Q: WHAT HAPPENS IF THE PAIN GETS WORSE?**

If the pain gets worse, your hospice team has several choices including:

1. Increasing the medication dose.
2. Changing medications.
3. Adding another medication- sometimes different drugs work well when taken together.
4. Other non-medication management such as meditation, relaxation, massage.

**It is very important to talk with your hospice nurse or physician about your pain. DO NOT make any medication changes yourself. Please be aware it may take a little time to adjust your pain medicine to achieve the best relief.**

### **Q: WILL I GET DROWSY IF I TAKE PAIN MEDICINE?**

Sometimes pain medicines can make you feel drowsy at first. Often this goes away after a few days as your body adjusts. If your pain has made you lose sleep, you may finally get to catch up on much needed rest. Check with your nurse if the drowsiness lasts more than a few days or the medication makes it difficult to wake up.

### **Q: WHAT IF MY PAIN MEDICATION MAKES ME SICK TO MY STOMACH?**

Sometimes pain medication can upset your stomach. This is another problem which may just last a few days. If it does not go away, check with your nurses about ways to decrease the nausea or other stomach issues.

## Q: WHAT IF I GET CONSTIPATED?

Many pain medications have side effects. Constipation is a common side effect of many medications called opioids. Our protocol includes adding a laxative in the pain management regimen to prevent this side effect. Check with your nurse before using any laxative.

## Q: HOW DO I AVOID CONFUSION?

Your hospice team will be monitoring you for signs of this. Mental confusion may mean the amount of medication you are receiving needs to be adjusted. Please call us about problems with confusion.

# Caregivers & pain management

## WHAT CAREGIVERS CAN DO TO HELP WITH PAIN MANAGEMENT

### COMFORT MEASURES SUCH AS:

- Relaxation techniques
- Assistance with care
- Massages
- Change the patient's position

### PREPARE THE ROOM TO PROVIDE PERIODS OF REST. INCLUDING:

- Making the room dark
- Quiet time
- Time alone/period of uninterrupted sleep
- Position for comfort

**SPEND TIME TALKING WITH THE PERSON** about what is causing the pain/discomfort.

**HELP ENSURE MEDICATION IS TAKEN AS DIRECTED** by the physician.

**AS PAIN BECOMES LESS**, encourage more activity.

**OFFER/ACCEPT EMOTIONAL SUPPORT.**

## WHAT NOT TO DO

- Do not take more pain medications than what is prescribed without first consulting with your nurse
- Do not suddenly stop giving pain medications or other medications
- Do not ignore or overlook the pain or discomfort

## WHEN TO CALL THE HOSPICE NURSE

- If any new or severe pain occurs
- If the patient develops hearing or seeing people or things that are not there
- If pain or discomfort is not controlled by present medication schedule
- If you have any questions about the medications

## Pain diary

You may find it helpful to keep a record or a diary about your pain and what you try for pain relief. The record helps you and those who are caring for you understand more about your pain, the effects it has on you, and what works best to ease your pain. Items that should be included are:

- The number from your rating scale that describes your pain before and after using a pain-relief measure.
- The time you take pain medicine.
- Any activity that seems to be affected by the pain or that increases or decreases the pain.
- Any activity that you cannot do because of the pain.
- The name of the pain medicine you take and the dose.
- How long the pain medicine works.
- Any pain relief methods other than medicine you use such as rest, relaxation techniques, distraction, skin stimulation, or imagery.

**A Pain Diary form is in Section 11 of this guide for you to use.**

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# MEDICATION SAFETY



# 3 MEDICATION SAFETY

## Medication safety

### TAKING YOUR MEDICATION CORRECTLY AND AS PRESCRIBED WILL GIVE YOU THE BEST RESULTS. HERE ARE SOME TIPS

**MAKE A COMPLETE LIST OF ALL YOUR CURRENT MEDICATIONS** including prescriptions, over the counter medications, vitamins and herbal supplements. Always keep this list updated and bring it with you to all medical appointments. A medication list form is in Section 11 of this guide for you to use.

**KNOW THE NAME OF EACH OF YOUR MEDICATIONS**, why and how you take it, potential side effects and what food/beverages or other medications you need to avoid. **If you are unsure, please ask your nurse or hospice team member.**

**REPORT ANY ALLERGIC RESPONSE OR SIDE EFFECT** to your nurse or hospice team.

- Signs and symptoms of a serious drug allergy often occur within an hour after taking a drug
- Drug allergy signs and symptoms may include: skin rash, hives, fever, swelling, shortness of breath, wheezing, runny nose and itchy, watery eyes.

**SIGNS AND SYMPTOMS OF A SEVERE, LIFE-THREATENING REACTION TO A DRUG ALLERGY MAY INCLUDE:**

Tightening of the airways and throat, causing trouble breathing; weak, rapid pulse; seizure; loss of consciousness.

- Call 911 or emergency medical help if you experience signs of a **severe reaction** after taking a medication.

**AVOID SKIPPING MEDICATIONS;** take all medications as prescribed.

- Do not take medications prescribed for someone else- even if you think it is the same medication.
- Do not use alcohol when you are taking your medication.

*Create a “Medication Safety Zone” in your home – a dedicated area where medications are prepared, administered or consumed. To promote safety, it should feature:*

**ADEQUATE LIGHTING:** It is important that medicines be prepared in a well-lit area. Since the lighting in most homes is lower than recommended for reading, it is good to place an adjustable 50-watt high-intensity task light in the area where you handle medications.

**MINIMAL DISTRACTIONS AND/OR INTERRUPTIONS:**

Interruptions and distractions (*including noise*) are among the leading causes of prescription dispensing and medication errors in hospitals and health systems (45%). So, when preparing or administering medication at home, it is equally **important to silence your cell phone, turn off the radio and/or TV and choose a time when you know you are not pressed for time and interruptions are less likely.**

**A TIDY & ORGANIZED WORKSPACE:** Dispensing errors occurred when medications were stored in a cluttered fashion, so neatness counts. Materials should be organized so that:

**IMPORTANT INFORMATION IS READILY AVAILABLE —** information about equipment function is located near or even on the equipment.

**GROUP ITEMS TOGETHER —** Frequently used items should be easily accessible. Group items together such as: storing syringes, needles and alcohol swabs together in a single bin.



### STORE MEDICINES ACCORDING TO DIRECTIONS —

Most medicines should be stored in a cool dry place well away from moisture (i.e. not the bathroom). But some medications require special storage conditions such as refrigeration – if so, create a “medication safety zone” in your refrigerator that is designated for medicine storage. If in doubt, always follow the storage directions contained on the medicine label or the Medication Guide.

*Prescription Labels That are Easy to Read & Understand:*

**IMPAIRED VISION** – ask for the label to be printed in a larger font.

**NON-NATIVE ENGLISH SPEAKER** – ask for the label to be printed in your language of choice. (*But the drug name should always be in English to help emergency personnel.*)

**PURPOSE FOR USE** – patients can request that doctors and pharmacists include this information on the prescription label to help prevent medication errors and encourage adherence.

**PATIENT INFORMATION LEAFLETS** (*also called “Medication Guides”*) should be kept together, perhaps in a large re-sealable plastic bag, so that the patient and others can easily access instructions. These may also be available in large type (*or alternate languages*) – ask at the pharmacy.

*A “System” That Works for the Patient:*

**IF YOU RELY ON ICE-CUBE-TYPE PILL BOXES**, can the patient pop open the lid (*if he/she is self-administering them*)?

**HAVE A BACK-UP PLAN** if some medications fall out.

**TO HELP THE PATIENT RECORD WHEN THEY TAKE HIS/HER MEDICATION**, use a small notebook with the day or date already written, so the patient only must make a check-mark.

**Tech-savvy patients and healthcare professionals can explore Skype and medication-reminder apps.**

## *Safe Disposal of Medications*

Medication safety is an important concern for our nation and Capital Caring Health. Capital Caring Health provides a medication deactivation and disposal product to our patients receiving care at home. This product is intended to be used when prescription medications are discontinued, or after the patient has died. In Maryland and Virginia, we are required to follow a medication disposal process. While the District of Columbia does not currently require this, we believe it is safe and prudent practice.

If a Capital Caring Health nurse comes to your home when your loved one has died, they will request your permission to dispose of prescription medications for the patient. You will be asked to sign a consent form granting or declining permission. You or someone else in the home will be asked to witness this process as the nurse counts and disposes of each medication. Should you elect to decline, we are required to count the quantity of each prescription medication as well as teach you the importance of medication disposal.

*Review the following pages for additional information about Safe Disposals of Medications including the:*

· Deterra Drug Deactivation System



# Deterra® Drug Deactivation System Frequently Asked Questions (FAQ's)



## How does Deterra® work?

Each patented Deterra® pouch contains a water-soluble inner pod containing MAT<sub>12</sub>® activated carbon. Once the pharmaceuticals are placed in the pouch, warm water is then added, which dissolves the inner pod releasing the activated carbon. The warm water also dissolves prescription pills, patches and liquids, allowing them to be adsorbed by the carbon, rendering them inert and non-retrievable.

## What drugs will Deterra® deactivate?

Deterra® will deactivate any organic medications including opioids. However, it will not adsorb any metals, such as iron or lithium, contained in certain medications. If a select medication has specific disposal instructions, please follow those instructions.

## Why shouldn't I just flush or "sink" unused meds?

Water treatment facilities struggle to filter out all pharmaceutical drugs from the water. As of 2014, there were over 1,500 published reports of the occurrence of pharmaceuticals in sewage, surface waters, ground waters, and elsewhere. Because of these findings, most federal, state and local authorities are now recommending (and many requiring) that pharmaceuticals NOT be disposed in the toilet or sink.

## What about mixing medications with cat litter, coffee grounds or sawdust? How does that compare?

Cat litter, coffee grounds, and sawdust make the drug undesirable but do not deactivate the drugs. Once in the landfill, these drugs can still leach out into the ground and into the water. Third party testing proves that the MAT<sub>12</sub>® carbon in Deterra® deactivates the drugs rendering them inert and more environmentally friendly.

## How quickly does the deactivation process work?

With Deterra®, the process of deactivation starts immediately, but it takes time to complete. Some highly soluble drugs will dissolve and react rapidly, while other less soluble drug types will take longer to dissolve and react. The deactivation period varies based on volume and type of medication. It is important to keep Deterra® out of the reach of children and pets as the product is deactivated.

## Are different sizes of Deterra® available?

Yes, Deterra® is available in multiple sizes. Please consult our website or a Deterra® representative to determine which size will best meet your needs. [www.deterrasystem.com](http://www.deterrasystem.com)

## What is the capacity of Deterra® for pharmaceuticals? What if I accidentally added more drugs than the amount recommended?

The recommended capacity is listed on each Deterra® package. Adding drugs to Deterra® in amounts at (or less than) our recommended capacity will result in optimal deactivation efficiency. If one were to add more than the recommended pharmaceutical capacity, deactivation of additional drugs will still occur but at reduced efficiency.

## What would happen if I didn't add water?

The water-soluble pod located inside the pouch will not open and expose the carbon to the medication. Warm water will also help to dissolve pills and draw the drugs out of patches. The absence of water will not allow the deactivation process to begin. Please follow the directions on the back of the pouch.

## Are the Deterra® active ingredients safe?

The granular activated carbon used in Deterra® is non-corrosive to the skin or the eyes. The carbon is considered non-flammable and is stable under normal conditions in shipment, storage and use. There are no known harmful effects associated with ingestion of the carbon. It is considered non-toxic. A link to the most current MSDS is available on our website; [www.deterrasystem.com](http://www.deterrasystem.com)

## Does carbon release the drug if exposed to heat or solvent?

Based on testing, back extraction of the deactivated drugs is not effective. When used properly, the activated carbon will retain the drugs, rendering the contents of the Deterra® pouch inert and non-retrievable.

## Aren't we just adding another plastic bag to landfills? Isn't the incineration of unused pharmaceuticals the best for the environment?

The Deterra® drug deactivation pouch is made from environmentally friendly materials. This allows for the degradation of the plastic pouch through the use of an organic additive that reacts with the microbes found in the landfill. The result is the release of water and carbon dioxide, with little organic biomass left behind. This greatly reduces the amount of material left in landfills. The incineration process releases global warming and smog inducing gases, ozone depleting agents, carcinogenic compounds, and other by-products.

## Have Government Agencies endorsed Deterra®?

Government agencies do not endorse specific products. However, Verde has been awarded a contract from the National Institute on Drug Abuse (NIDA), a part of the U.S. National Institute of Health (NIH), for the development of a cost effective, easy to use at-home drug deactivation system. Following the Phase 1 product evaluation and full report, NIDA then awarded the Phase 2 contract to Verde to commercialize these products. In addition, the Office of National Drug Control Policy recently revised their National Drug Control Policy to include support of "At-Home Drug Deactivation Systems" for use in safely removing unwanted drugs from the home. The Department of Justice and the Drug Enforcement Administration in Northern Alabama have distributed Deterra® as a means for people to dispose of drugs as needed.

## How can I comply with local environmental regulations?

In-home drug disposal is generally unregulated by federal, state and local authorities. Customers using Deterra® institutionally should follow all federal, state and local regulations. We have found state and local authorities to be very helpful, and they can conveniently be contacted for questions.

## I work in a Healthcare Facility with a DEA registration. We encounter the need to dispose of controlled substances. Can I use Deterra® for this purpose in compliance with my registration?

According to the DEA, any destruction method applied to a controlled substance must render it "non-retrievable" and subsequently unavailable, unusable, and no longer available for diversion for all practical purposes. Testing results have shown Deterra® to meet these standards. Ultimately, it is up to the individual waste generator to ensure that they comply with all local, state and federal regulations.

# PREVENTING INFECTION



# 4 PREVENTING INFECTION

Staying clean and using good hygiene helps stop the spread of infection especially for those with certain illnesses such as leukemia, diabetes and those who have had treatments such as chemotherapy and dialysis. Items used in healthcare such as bandages or gloves can spread infection and harm others if not disposed of properly. Your nurse will tell you how to use protective clothing if you need it.

## IMPORTANT—TELL YOUR PHYSICIAN AND/OR HOSPICE STAFF IF YOU NOTICE ANY OF THE FOLLOWING SIGNS OF INFECTION

- Pain, tenderness, redness or swelling of a body part
- Inflamed skin, rash, sores
- Pain when urinating
- Confusion
- Nausea, vomiting or diarrhea
- Fever or chills
- Sore throat or cough
- Increased tiredness or weakness
- Green or yellow pus/ drainage

## HAND HYGIENE/ WASH YOUR HANDS

Wash your hands frequently and correctly, even if you wear gloves. It is the **single most important** step in controlling the spread of infection.

*Always wash hands before:*

- Caring for a sick person
- Treating a cut or wound
- Touching or eating food

*Always wash hands after:*

- Caring for a sick person
- Treating a cut or wound
- Using the bathroom/changing diapers
- Touching animals or their waste
- Touching soiled linens and/or garbage
- Coughing, sneezing or blowing your nose

*Hand Hygiene/WASH YOUR HANDS*





## Covering your cough

Cover your mouth and nose with a tissue when you cough or sneeze. If you do not have a tissue, cover your mouth with your upper sleeve, not your hands. Throw your used tissue in the trash. You may be asked to wear a mask to protect others.

## Cleaning correctly

### BLOOD AND OTHER BODY FLUIDS

Blood and body fluid spills are cleaned by putting on gloves and wiping the fluid with paper towels. Use a solution of 1 cup of household bleach to 10 cups of water to wipe the area again. Double bag the used paper towels and dispose of them in the trash.

### NON-DISPOSABLE (CANNOT BE THROWN AWAY) ITEMS/EQUIPMENT

**SOILED LAUNDRY:** should be washed apart from other household laundry in hot, soapy water. Handle these items as little as possible to avoid spreading germs. Household bleach should be added if the patient had/has a viral illness (1 cup bleach to 10 cups water).

**ITEMS SUCH AS:** thermometers, toilets, walkers, wheelchairs, bath seats, suction machines, oxygen equipment and mattresses are considered non-disposable. Any of these used by the patient should be cleaned immediately after use. Household cleaners may be used to wipe off the equipment. Follow the instructions that came with the equipment and discuss with your clinical team if you have questions.

**LIQUIDS:** Pour liquids in the toilet. Clean the containers with hot, soapy water, rinse them with boiling water and let them air dry.

Not Visibly Dirty Hands:  
Use of an Alcohol-Based Hand Sanitizer

### WHEN USING ALCOHOL-BASED HAND SANITIZER:



Put product on hands and rub hands together



Cover all surfaces until hands feel dry



This should take around 20 seconds

## DISPOSABLE (THROW AWAY) ITEMS/ EQUIPMENT

Items such as the following must be disposed of in a waterproof plastic bag and then bag it again (double bag). Fasten it securely and dispose of the bag in the trash. Your clinical team will instruct you on how to dispose of biomedical waste in accordance with your area's regulations.

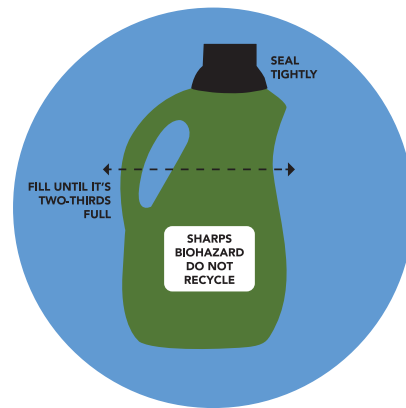
- Tissues
- Dressings
- Soiled bandages
- Diapers
- Plastic equipment or tubing

## Sharp objects

Items such as the following must be placed into a clean, rigid container such as hard plastic or metal with a screw-on or tightly secured lid. **NEVER overfill the container or recap needles** once used.

- Needles
- IV catheters with needle attached
- Syringes
- Lancets/razors
- Scissors
- Knives
- Staples
- Glass tubes/bottles

**DO NOT USE glass or clear plastic containers and NEVER put sharp objects in a container that will be recycled or returned to a store.** Seal the container with tape and place it in the trash can or dispose of it according to area regulations.



## Resistant bacteria

Multi-drug Resistant Organisms (MDROs) are bacteria that are resistant to one or more classes of antibiotics. The most common are Staph infections known as MRSA (Methicillin Resistant Staphylococcus Aureus). Typical Staph infections are common and usually respond to antibiotics. MRSA infections do not.

## ANYONE CAN GET A STAPH INFECTION IF THEY HAVE

- Skin to skin contact with someone infected.
- Contact with items and surfaces with Staph on them.
- Openings in their skin such as cuts/scrapes.
- Crowded living conditions.
- Poor hygiene.

## TO PREVENT ACQUIRING OR SPREADING A STAPH INFECTION

- Wash your hands often.
- Keep your cuts/scrapes clean and covered with bandages.
- Do not touch other people's cuts or bandages without proper precautions.
- Do not share personal items like towels or razors.

FOR MORE INFO, PLEASE VISIT: [www.cdc.gov/ncidod/dhqp/ar\\_mrsa.html](http://www.cdc.gov/ncidod/dhqp/ar_mrsa.html)

# NOTES

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# CAREGIVER/ PATIENT CARE INFORMATION



# 5 CAREGIVER/PATIENT CARE INFORMATION

## *Food and nutrition*

Any person with a serious illness may find they do not feel like eating as much as normal or not at all. If you are experiencing nausea, vomiting or pain which prevents you from eating, tell your hospice nurse. When your symptoms are controlled, your appetite may return.

Loss of appetite may be difficult for you and your family/caregivers. Here are some tips to help manage nutritional needs.

- Eat as much or as little as you want. Gentle encouragement from your family and caregivers is good, but they should not pressure you to eat.
- Do not eat large meals. Instead, eat small, frequent meals of your favorite foods.



### EAT FOODS WITH HIGH NUTRITIONAL VALUE:

- Peanut butter on toast
- Whole milk
- Two (2) slices of cheese on grilled sandwich
- Regular soda instead of diet soda
- Keep snacks nearby for when you feel like eating.
- Drink liquids during the day- even if you do not want to eat. Choose liquids that add calories- juice, soup, milk, etc...
- Eat soft, cool foods including yogurt, milkshakes and popsicles.
- Avoid greasy foods and rich sauces or those with a lot of spices or seasoning.
- Avoid foods when nauseated. Avoid overly sweet and salty foods.
- Eat a bedtime snack. This will give extra calories but will not affect your appetite for the next meal.

**Discuss any concerns with your hospice nurse who can provide you with additional information regarding nutrition and intake. If needed, a nutritionist can be consulted to meet your specific needs.**

# Symptom control/ comfort measures

Make sure to discuss symptom control with your hospice nurse and team. Please report any new symptoms or change in existing symptoms to your nurse/team.

## RESPIRATORY

### SHORTNESS OF BREATH

- Calmly provide reassurance and provide frequent rest periods
- Position upright (high) position in bed or chair
- Place a fan near the patient to keep the room comfortably cool
- Take medications and use oxygen as ordered

**Call your nurse if there are ANY changes in breathing, regardless of the time of day or night.**

### COUGH

- Take cough medicine as ordered
- Use sips of fluid and hard candy (when appropriate) to keep mouth moist

### CONGESTION

- Elevate head of the bed and position on side or upright; take deep breaths and cough (if able)

## GASTROINTESTINAL (MOUTH, STOMACH, BOWEL)

### DRY MOUTH

- Offer frequent small sips of fluid and/or ice chips
- Keep teeth/tongue clean & apply lip balm

### MOUTH SORENESS

- Offer bland, soft food (avoid spicy or acidic)
- Avoid alcohol-based mouthwash

**Report white patches in mouth or throat to the nurse**

### PROBLEMS SWALLOWING

- Use softer, blended foods (thinner liquids are more difficult to swallow)
- Avoid milk products (can increase mucus)

**Any other issues or changes, notify the nurse immediately.**

### NAUSEA/ VOMITING

- Eat small amounts of bland food
- Take ordered medicine at the start of nausea

### CONSTIPATION

- Use laxative as ordered
- Increase fluid intake if tolerated
- Eat fish, fresh fruits and whole grains if possible

**Call your nurse if patient has had no bowel movement for three (3) days or has any of these symptoms:**

- **Stomach distention or bloating**
- **Rectal pain with bowel movement**

### DIARRHEA

- Clean skin frequently and carefully & apply protective ointment to skin
- Eat bland foods such as bananas, rice, applesauce and toast if possible
- **Call your nurse if patient has sudden onset of diarrhea and/or fever.**

## URINARY

### INCONTINENCE (LOSS OF BLADDER CONTROL)

- Keep skin clean and dry; change briefs as soon as you notice they are wet
- Elevate head of the bed and position on side or upright

## NERVOUS SYSTEM (THOUGHT PROCESS, PHYSICAL ACTIVITY)

### DIZZINESS

- Move patient slowly from lying to sitting to standing position

**Discuss care with nurse**

### CONFUSION

- Offer reassurance; speak softly and calmly

**Discuss safety plan to prevent falls with nurse and team**

## SKIN

### DRY SKIN

- Avoid daily bathing (every other day is ok)
- Apply moisturizer after bathing

### IRRITATION/REDNESS

- Keep skin and skin folds dry and clean
- Protect bony areas with pillow or blankets
- Speak with the nurse before using a heating pad or cold application

**Report redness or breaks in skin to the nurse**

## EMOTIONS

### FEELING ANXIOUS

- Be with the patient; provide support
- Relieve physical discomfort
- Give medicine as ordered
- Offer distraction as tolerated and appropriate

### FEELING SAD

- Offer gentle support; allow discussion of feelings
- Give medicine as ordered
- Have a discussion with the social worker and/or chaplain

**Notify nurse of any increased sadness**

### DIFFICULTY SLEEPING

- Relieve pain
- Avoid caffeine
- Use massage, bathing, music and other relaxation techniques
- Give medicine as ordered

**Notify nurse of any changes in sleeping pattern**



# SAFETY & EMERGENCY PLANNING





# 6 SAFETY & EMERGENCY PLANNING

**In the event of a natural disaster, inclement weather or other emergency, we have an emergency operation plan to continue necessary patient services. We will make every effort to continue home care visits; however, the safety of our staff must be considered. When roads are too dangerous to travel, our staff will contact you by phone, if possible, to let you know they are unable to make your visit that day. Every possible effort will be made to ensure your medical needs are met.**

## *Emergency operation care plan*

During the admission visit, and periodically thereafter as patient needs change, staff will assist you in developing a plan for essential care to be administered during a state of emergency if staff cannot travel to see you. All staff members will understand and utilize the Emergency Preparedness Care Plan (Patient Classification System). Emergency plans may include, but are not limited to:

**EVACUATION TO A SHELTER**— patients are instructed to take medications, medication list and DNR paperwork, as well as supplies and equipment needed for several days.

**OBTAINING ALTERNATE POWER SOURCES**, such as batteries and electrical generators, for essential medical equipment.

**MAINTAINING ONE-WEEK SUPPLY OF MEDICATIONS AND MEDICAL SUPPLIES, AT ALL TIMES.**

**IDENTIFYING AN ALTERNATE PERSON** for training as a back-up caregiver.

**EVACUATION TO FAMILY OR FRIENDS OUTSIDE THE AREA**, with specific directions for care to be delivered by an agency serving that area or alternate caregiver training.

**EVACUATION TO A HEALTH-CARE FACILITY** serviced by supplementary power.

**ALL PATIENTS AND FAMILIES NEED TO TAKE SPECIAL PRECAUTIONS TO ENSURE A SAFE LIVING ENVIRONMENT. MOST EMERGENCY SITUATIONS CAN BE PREVENTED BY ELIMINATING HAZARDS AND BEING PREPARED. REMEMBER TO:**

- Keep all emergency numbers near the phone. If possible, have a cordless and/or a cell phone with speaker capability and speed dial memory. Program all emergency numbers so you only need to press one button in an emergency to get help.
- Keep in touch with others; ask someone to check on you- especially if you live alone.
- Keep an intercom or baby monitor near so you can hear your loved one when you are in another room.



## *Home safety/ fall prevention*

Are you at risk for falls? At least half of all falls happen in the home. They are often due to hazards that are easily overlooked but easy to fix. Your chances increase with any of the following factors:

- History of falls (2 or more in the last 6 months)
- Medications (4 or more)
- Vision and/or hearing loss
- Inactivity/decreased mobility/use of a walker
- Balance issues
- High or low blood pressure
- Foot pain/ Shoe problems
- Mental status changes
- Safety hazards inside or outside home

### **HOME SAFETY**

- Keep poison control center number readily available.
- Keep all hazardous items, cleaners and chemicals out of reach of children and confused or impaired adults.
- Keep pathways clear of things that could trip you.
- Ask someone to rearrange furniture to keep walkways clear.
- Remove loose throw rugs or secure them with double sided tape.
- Make sure furniture is stable – anything with wheels should be in the locked position.
- Keep phones on low level tables.
- Clean up spills immediately. Do not walk on wet surfaces.
- Always be aware of where your pets are.
- Keep items used often within easy reach (waist high).
- Avoid climbing; use step stool if necessary.
- Never use a chair as a step stool.
- Have phone within easy reach of bed.
- Have lamp or light switch within easy reach of bed.
- Consider a bedside commode.
- Have sturdy handrails on both sides of the entire staircase.
- Make sure all steps are in good repair. Replace loose, worn or broken steps.
- Firmly attached carpeting on all stairs if possible; if not, use non-slip rubber treads.



## PATIENT MOVING SAFETY

*Caregivers helping transfer patients safely, remember to:*

- Let the person do as much work as he/she can.
- Use a transfer belt to balance and support the person.
- Have the person wear shoes with good treads or sturdy slippers.
- Ask for training.
- Back strain and back pain are common problems that occur when helping with transfers. Moving a person the wrong way is one of the main reasons this happens.

*If you are transferring yourself or helping with your own transfer:*

- Wear shoes with good treads or sturdy slippers, unless otherwise directed by your healthcare provider.
- Contact your nurse or the company that supplied you with your device if you need additional information about moving aids such as: transfer boards or special lifts to move you from your bed to chair or wheelchair. The company that supplies you with your device may send someone to teach you how to use it.

*These tips may help transfer a patient in or out of a bed or chair safely:*

- Plan the move and know what you can and cannot do.
- Tell the person what you are going to do.
- Before starting a move, count with the person, “1-2-3”.
- Place transfer surfaces (wheelchair and bed) close together.
- Check the wheelchair. Are the brakes locked? Are armrests and footrests swung out of the way?
- Let the person look at the place where they will be transferred to.
- If the person is able, place their hands on the bed or chair so he/she can help with the movement. If the person has had a stroke or is afraid, have him/her clasp his/her hands close to his/her chest.
- While lifting, keep your back in a neutral position (arched normally, not stiff), knees bent, weight balanced on both feet. Tighten your stomach and back muscles to keep the correct support position.
- Use your arms to support the person.
- Let your legs do the lifting.
- Turn on one foot instead of twisting your body.



## Using a walker

There are many types of walkers. Some walkers have no wheels, 2 wheels, or 4 wheels. Some walkers have brakes, a carrying basket, and a sitting bench.

If your walker has wheels, you will push it forward to move forward. If your walker does not have wheels, then you will need to lift it and place it in front of you to move forward. All 4 tips or wheels on your walker need to be on the ground before you put your weight on it. **Ask us for help if you are having problems using your walker.**

- Look forward when you are walking, not down at your feet.
- Use a chair with armrests to make sitting and standing easier.
- Make sure your walker has been adjusted to your height.
- The handles should be at the level of your hips. Your elbows should be slightly bent when you hold the handles.
- Keep space between you and your walker and keep your toes inside your walker. Stepping too close to the front, tips or wheels may make you lose your balance.
- Make sure any loose rugs, rug corners that stick up, or cords are secured to the ground, so you do not trip or get tangled in them.

- Wear shoes or slippers with rubber or other non-skid soles. **DO NOT** wear shoes with heels or leather soles.
- Attach a small bag or basket to your walker to hold small items so that you can keep both hands on your walker.

### STANDING WITH A WALKER

1. Push up from the armrest of the chair or from the bed to a standing position.
2. Place a firm grip on both sides of the walker with your hands.
3. Move the walker forward a short distance.
4. Step forward with your injured or weaker leg first, putting weight on the palms of your hands. Then take a step with your stronger leg. Keep your feet within the boundaries of the walker.

### TURNING WITH A WALKER

Take small steps when you turn by moving the walker a short distance, then your legs. You may also turn by walking with a walker in a big circle.

## WALKING WITH A WALKER

*Follow these steps to walk with your walker:*

1. Push or lift your walker a few inches, or a few centimeters, or an arm's length in front of you.
2. Make sure all 4 tips or wheels of your walker are touching the ground before taking a step.
3. Step forward with your weak leg first. If you had surgery on both legs, start with the leg that feels weaker.
4. Then step forward with your other leg, placing it in front of the weaker leg.
5. Repeat steps 1 through 4 to move forward. Go slowly and walk with good posture, keeping your back straight.

## STANDING TO SITTING WITH A WALKER

*Follow these steps when you sit down:*

1. Back up to your chair, bed, or toilet until the seat touches the back of your legs.
2. Make sure all 4 tips or wheels of your walker are touching the ground.
3. Reach back with one hand and grab the armrest, bed, or toilet behind you.
4. Lean forward and move your weaker leg forward.
5. Slowly sit down and then slide back into position.

## STEPPING UP OR DOWN A STEP OR CURB WITH A WALKER

1. When going up a step or curb, start with your stronger leg. When going down a step or curb, start with the weaker leg: "Up with the good, down with the bad."
2. Place your walker on the step or curb in front of you if you are going up. Place it beneath the step or curb if you are going down.
3. Make sure all four tips or wheels are touching the ground.

4. To go up, step up with your strong leg first. Place all your weight on the walker and bring your weaker leg up to the step or curb. To go down, step down with your weaker leg first. Place all your weight on the walker. Bring your strong leg down next to your weaker leg.

## Bathroom safety

- Use non-skid mats or strips in tubs and showers to prevent falls.
- Install night lights and grab bars in showers, tubs and toilet areas.
- Always check the water temperature before entering tub or shower.
- If unsure about ability to use bathroom facilities alone, including bathing, notify your nurse.

## Power outage

Go to the web page for your power company for the information required to register for a serious medical condition if your family member requires constant use of electricity.

Always remember to have flashlights and extra batteries in a handy spot. Also have a fully charged portable or cell phone available at all times.

## IF YOU NEED HELP IN A POWER OUTAGE AND CAPITAL CARING HEALTH'S PHONE LINES ARE DOWN

- Call 911 or go to the nearest emergency room if you have an emergency.

## Medical equipment safety

- Post medical equipment (DME)/emergency numbers near telephone.
- Read the manufacturer's instructions and keep near the equipment at all times.
- Perform routine cleaning and preventative maintenance per the manufacturer's instructions.
- Have backup equipment available, if necessary.
- Properly install all supportive or safety equipment such as bed or shower rails. Do not use as a substitute for supervision or physical assistance.

If bed rails are split (*see image*) remove or leave the foot end down so the person does not become trapped between the rails.



## Oxygen safety

Now that you are home with oxygen there are a few safety considerations to keep in mind.

1. To identify safety risks to individuals entering your home, a “No Smoking, Oxygen In Use” sign should be posted in a prominent location.
2. Smoke detectors should be present (preferably on each floor) and functional. Change batteries regularly.
3. A fire extinguisher should be accessible and functional.
4. You and your family should discuss an evacuation route from the house in the event of a fire. Plan an alternative route and practice them.
5. Equipment should be set up and stored safely.
  - Oxygen concentrators should be 8-10 inches from walls or curtains to prevent obstruction to flow. All oxygen equipment should be used in a well ventilated area.
  - Make sure you are a safe distance from the machine so that you would hear any alarms that may occur. Tubing should not exceed more than 50 feet to help prevent entanglement or tripping (25 feet for pediatric patients) and area should be free of clutter.
  - A grounded outlet should be used. Refrain from using extension cords and do not plug a concentrator into a receptacle which can be controlled by a light switch. All cords should be in good condition and never frayed or damaged.
  - Oxygen should not be used or stored within 10 feet of an open flame or heat source such as a gas stove, grill, electric skillet, fireplace, candle or smoking.
  - Any oxygen tanks for back up use should be stored in a secure upright position such as an approved stand or secured horizontally. Store tanks in a well ventilated area. Do NOT store oxygen tanks in a closet. Turn valves off when oxygen is not in use. Make sure back up tanks are easily accessible in the event of emergency.
  - Pets and small children should be kept away from oxygen equipment to avoid altered settings.
6. For mobility with oxygen, an approved cart or carrying bag may be used. When traveling, extra tanks should be secured on the floor of the vehicle. Keep windows cracked in a parked car and never store tanks in the trunk of a vehicle.
7. If you are using an oxygen concentrator, external filters should be cleaned once a week and as needed to ensure proper air flow.
8. **You should never smoke while wearing oxygen.** Others should not smoke in the same house/apartment or any indoor space where you are.
9. Due to combustibility, do not use aerosol sprays such as hairspray in the presence of oxygen.

10. Oil and grease products should never come in contact with your oxygen. Petroleum based products can become explosive under pressure and pose a fire risk. Only water-soluble lotions and creams should be used on your body.
  11. There is a risk of spark with some electrical devices. Do not have oxygen in the presence of devices such as a hair dryer or electric razor.
  12. Know your emergency numbers. Once home, you should notify your local fire and ambulance companies of special needs. Know your homecare provider's number and keep a close check on the amount of back up oxygen you have on hand.
  13. Whenever planning travel, make sure you contact your homecare provider to make any arrangements necessary.
  14. Always follow your doctor's prescription. Do not adjust your oxygen flow rate without contacting your physician. Never attempt repair of any oxygen unit. Address any concerns or questions to the homecare provider.
- Avoid excess clutter of newspapers, magazines, clothing, etc. These piles can become a fuel source for potential fires.
  - Make a family fire escape plan and practice every six (6) months. Plan at least two (2) ways to get out of the home from each room with all family members.
  - If you live in an apartment building, know where the exit stairs are located. **DO NOT USE THE ELEVATOR IN A FIRE EMERGENCY.**
  - Designate a safe place in front of the house or apartment building for family members to meet after escaping a fire.
  - If your fire escape route is cut off, remain calm, close the door and seal the cracks to hold back smoke. Signal for help at a window if possible.

**ALSO REMEMBER TO:**

- Have your heating systems checked and cleaned by a professional regularly.
- Wood-burning stoves and fireplaces should be properly installed and maintained.
- Keep portable electric or kerosene heaters out of high traffic areas. Operate them on the floor at least three (3) feet away from furniture, drapes and bedding.
- Turn portable heaters off when leaving the house or going to sleep.
- Use kerosene heaters **ONLY** in well-ventilated rooms and store kerosene outside in a tightly sealed, labeled container.

## *Fire safety/ Burn precautions*

- Make sure the patient has easy access to a telephone and post the fire department number on every telephone. **All family members and caregivers should be familiar with emergency 911 procedures.**
- Notify the fire department if a disabled person is in the home as soon as possible.
- **DO NOT SMOKE (including e-cigarettes) in bed or where oxygen is being used.** Never leave burning cigarettes unattended. Do not empty smoldering ashes in a trash can. Keep ashtrays away from curtains and upholstered furniture.
- Install smoke detectors on every floor of your home, including the basement. Test every month to make sure they are working properly. Install new batteries two (2) times a year (SPRING and FALL).
- Fire extinguishers should be placed in the home and checked frequently for stability. Remember, life safety is **FIRST**, but if the fire is small and can be contained, you may be able to use your fire extinguisher until the fire department arrives.





## *Inclement weather safety*

### HOT WEATHER



- Stay indoors as much as possible, preferably in an air-conditioned room. If air conditioning is not available, stay on the lowest floor out of the sunshine.
- Drink plenty of fluids even if you do not feel thirsty and avoid alcohol or beverages which contain caffeine or sugar.
- If you take medications, check with your nurse and/or physician about the effects of sun and heat exposure.
- Plan outdoor activities for early or late in the day when the temperature will be cooler.
- Wear a high SPF sun block, wide brimmed hat and light-colored, loose fitting clothes when outdoors. Take frequent breaks.
- Sponge off frequently with cool water only.
- If you experience dizziness, nausea, headaches or muscle cramps, move to a cooler location, rest for a few minutes and slowly drink a cool beverage. Call us immediately if you do not feel better.
- Keep a bottle of water in your freezer. If the power goes out, move it to your refrigerator and keep the refrigerator doors shut.

### FLOODS



- Always be aware of flood hazards, especially if you live in a low-lying area, near water, or downstream from a dam. Flooding can take days to happen, but flash floods produce raging waters in minutes. Six (6) inches of moving water can knock you off your feet. Avoid moving water if you must walk in a flooded area. Use a stick to test if the ground is firm enough to walk on.
- Be ready to evacuate if a flood watch is issued. Move important items upstairs. Fill a clean bathtub with water in case water becomes contaminated or is shut off. Turn off your utilities at the main valves if you are instructed to do so. **DO NOT TOUCH electrical equipment if you are wet or standing in water.**



## SNOW EMERGENCY OR WINTER STORMS



- Keep car up-to-date on service; tank filled with gas
- Emergency supplies in car
- Battery powered radio
- Container of sand/rock salt
- Windshield scraper
- Flares
- Blanket
- Flashlight and Extra batteries
- Nonperishable food/snacks
- Manual can opener
- Medications
- Water
- Dress in layers of loose, lightweight, warm clothes rather than one heavy layer.
- Wear hats and outer layers which are tightly woven and water repellent. Mittens are warmer than gloves.
- Keep your cell phone charged.



## SEVERE WEATHER



- Store a 1-2-week supply of food/water on hand and consider any special dietary needs you may use. Place in water proof container.
- Store a 1-2-week supply of medication and/or medical supplies you will need.
- Know what to do if you are using medical equipment that runs on electricity and there is a power failure.

## TORNADO



**If a tornado warning is given,** go to the basement, storm cellar or interior space such as a closet or interior hallway. If you are in a mobile home or in your car, move immediate to a strong, safe structure. If not available, lie flat in the nearest, lowest ditch and cover your head.

## HURRICANE



If a hurricane is likely in your area, do the following:

- Make plans on how to secure your home. Storm shutter, boards for windows.
  - Be sure trees and shrubs are well trimmed
  - Clear loose and clogged rain gutters
- If a hurricane warning is given,** evacuate immediately. If you are unable to evacuate, follow these guidelines:
- Stay indoors away from windows and glass doors.
  - Close all interior doors
  - Keep curtains and blinds closed
  - Take refuge in a small interior room or closet

For more information on hurricane preparedness, visit: <https://www.ready.gov/hurricane-toolkit>

## EARTHQUAKE



If you are inside: get under a sturdy table and protect your head from debris. A wheelchair bound person should be moved to a doorway with the wheels locked and their head covered with their arms. If you are outside: move/park away from the building walls, power lines or trees until the quaking and aftershocks stop.

- **DO NOT** exit a building until instructed
- **DO NOT** enter damaged portions of a building until instructed.

## WILDFIRES



**If you see a wildfire, call 911 immediately.**

### BEFORE THE FIRE APPROACHES YOUR HOME

- Evacuate all pets and family members who are not essential to preparing the home.
- Wear protective clothing.
- Clear items that will burn easily: woodpiles, lawn furniture, etc.
- Close outside attic, eaves and basement vents and doors. Remove drapes and curtains. Open the fireplace damper.
- Connect garden hoses – fill any pools, tubs, cans or other containers with water.
- Place a ladder in front of the house in clear view.
- Back your car into the driveway and roll up the windows.

## PREPARING TO LEAVE

- Turn on outside lights and leave a light on in every room to make the house more visible in heavy smoke.
- Leave doors and windows closed but unlocked. Firefighters may need to gain quick entry to fight the fire. Place valuable papers and keepsakes and anything you “cannot live without” inside the car- ready for a quick departure.

**If you are trapped by fire stay inside and away from outside walls. Close doors but leave them unlocked. Keep your entire family together and remain calm. Call 911.**

## SHELTERS

**In an emergency, Capital Caring Health’s hospice team will continue to provide care to patients when at all possible. We will make every reasonable effort to ensure all patients who need continuing care receive it.**

*If you must evacuate to a shelter, please bring the following with you:*

- Bed Sheets, blankets, pillow(s), a folding chair, air mattress
- Medications, supplies and equipment including the phone numbers/contact information
- Personal snacks and drinks
- Glasses, hearing aids, batteries, prosthetics and any other assistive devices
- Extra clothing and personal hygiene items for 72 hours
- Flashlight and batteries
- Cell phone and charger

Caregivers who regularly assist the patient in the home are expected to continue to do the same in the shelter.

# PREPARING FOR APPROACHING DEATH/SUPPORT FOR CAREGIVERS



# 7 PREPARING FOR APPROACHING DEATH/SUPPORT FOR CAREGIVERS



## *As death nears*

During the stages of your loved one's advanced illness, we realize you may become more worried or concerned. We are here around the clock to assist you through this time and will answer any questions you may have.

## WHAT HAPPENS DURING THE LAST THREE (3) MONTHS OF LIFE

This is a time when the patient begins to want to put everything together, sometimes actively and sometimes unconsciously. You may see these behaviors:

- Getting his/her affairs in order
- Less interested in activities or acquaintances outside of family or close friends
- Eating decreases to smaller meals and preferred foods
- Sleeping more- 12-18 hours a day
- Much less active: if active one day, may sleep the entire next day

### *What can you do?*

If asked, help your loved one with what they request. Be respectful of his/her wishes regarding activities and visitors. Offer smaller meals and preferred foods, do not force them to eat.

## WHAT HAPPENS DURING THE LAST WEEK OF LIFE

As death approaches, your loved one will begin to show dramatic reduction in physical activity. At the same time, he or she might be talking more- or talking to people who are not in the room at the time. You may see these behaviors:

- Restlessness
- May talk about travel or getting ready to “go on a trip”
- Sleeping 20-23 hours a day
- Awake only brief periods at a time
- Talking to people who have already died
- May speak of angels in the room
- Eating little to no food
- Taking only sips of liquid
- May have brief periods of alertness and hunger
- Loss of ability to control urine and bowel movements

### *What can you do?*

Let your loved one know you are there, keep him/her comfortable, clean and in a quiet environment. Play soothing music, offer sips of preferred liquids, check every few hours for loss of urine or bowel movements. Let him/her know you will help make sure he or she is ready for “their trip” when the time is right. Share favorite stories. Give permission to die, say thank you, tell them how much you love and will miss them.

## WHAT HAPPENS DURING THE LAST HOURS OF LIFE (FINAL STAGES)

During this final stage of life, there are no right or wrong feelings.

**Call Capital Caring Health Hospice Services and speak to a nurse when you see the signs of approaching death; especially when your loved one’s breathing pattern changes, if there is difficulty swallowing, or if they become unable to awaken.**

**At this time, your presence is the MOST important thing you can give to your loved one.**

### *You may see these behaviors/changes:*

**BODY TEMPERATURE:** Your loved one may feel hot one minute and cold the next as the body loses its ability to control its temperature. As circulation slows down, you may also notice arms and legs becoming mottled/blotchy, cool and may be bluish in color. This is all a normal response to dying.

### *What can you do?*

Provide and/or remove blankets as needed. Provide a cool washcloth if this helps comfort the patient. Change sweaty garments and bed linens as needed. If the patient has a fever (*above 101.0° F*), call your nurse.

**BREATHING:** Breathing may become irregular with periods of no breathing for up to 20-30 seconds. You may also notice times which your loved one seems to be working very hard to breathe and may make moaning sounds with each breath. This is normal. It may not be a sign of pain or distress, but only the sound of air passing through the vocal cords.

### *What can you do?*

Raise the head of the bed/elevate head with pillows if it helps patient to breathe more easily.



**EATING/DRINKING/SWALLOWING:** Your loved one will have less interest in eating and drinking and the ability to swallow will diminish. This is normal, and the resulting dehydration does make your loved one more comfortable.

*What can you do?*

Offer, but do not force food, liquids or medications. Continue to perform mouth care to prevent dryness/cracking. Use vitamin E, Chapstick or Vaseline to soothe dry lips.

**LOSS OF BLADDER/BOWEL FUNCTION/DECREASE**

**URINATION:** The patient will lose the ability to control his/her bladder and bowel. In addition, urine output will decrease in amount and frequency. Urine will become darker.

*What can you do?*

Protect the mattress with a plastic cover and then a mattress pad/sheet. Keep waterproof padding under the patient and change as needed to keep him or her dry. Wash and dry the groin and rectal areas gently after each passage of urine and/or stool. Use skin care products as needed.

**CONFUSION/RESTLESSNESS:** Your loved one may become more confused or restless as less oxygen is available to supply to the brain. He or she may be disturbed by strange dreams or say a word or two that contains information or a request. He or she may try to get out of bed or speak with/see loved ones who have died.

*What can you do?*

Stay with your loved one as much as possible. Reassure them. Speak softly and hold his/her hand.

**SECRETIONS IN THE MOUTH:** Secretions may collect in the back of the throat and rattle or gurgle as the patient breathes. He or she may try to cough up these secretions unsuccessfully.

*What can you do?*

If the patient is trying to cough up secretions and is not successful, adding moisture to the air with cool mist vaporizer may help. It can also help to turn your loved one on his/her side.

**SLEEPING:** As the body weakens, your loved one will sleep more and begin to detach from his/her surroundings. Your attention to them may be ignored. This is normal.

*What can you do?*

Remember that at this stage, being with your loved one is more important than doing things for him/her. Let them sleep. Help them be positioned comfortably.

**UNCONSCIOUSNESS:** There may come a time when your loved one cannot respond to you. This is a coma or coma-like state and is normal in the dying process.

*What can you do?*

Turn and position him/her to be more comfortable, using pillows for support. Provide mouth care if it doesn't cause discomfort, massage skin with cream and keep the groin and rectal areas clean. Touching and speaking to your loved one may also be comforting.

**VISION/HEARING:** Your loved one's ability to see or hear may decrease and his/her speech may be difficult to understand.

*What can you do?*

Speak clearly, but softly. Keep the room dimly lit, even at night. Carry on all conversations as if they can be heard by the patient- hearing is the last of the sense to leave.

## *Other things you can do*

**GIVE PERMISSION:** Giving permission to your loved one to let go without making him or her feel guilty for leaving or trying to keep him or her with you to meet your own needs can be difficult. A dying person will normally try to hold on, even though this brings prolonged discomfort, to be sure that those who are being left behind will be alright.

Your ability to release the dying person from this concern and give him or her reassurance it is alright to let go whenever he or she is ready is one of the greatest gifts you can give your loved one at this time.

**SAY GOODBYE:** When the person is ready to die, and you can let go, then is the time to "say goodbye". Saying goodbye is your gift of love to your loved one, for it achieves closure and makes the final release possible. It may be helpful to lie in bed and hold him/her, or to take their hand and say everything you need to say. It may be a simple "I love you". It may be recounting favorite memories, places and activities you have shared. It may include saying "I'm sorry" or "Thank you".

**RELIGIOUS RITUALS:** If your loved one belongs to a faith tradition that practices end of life rituals, consider contacting a minister of his/her faith group or the Capital Caring Health Interfaith Chaplain to provide Spiritual Comfort in accord with their faith.


## *When death occurs*

- The patient cannot be awakened.
- The patient stops breathing and his/her heartbeat stops.
- His/her eyelids may be partially open with the eyes in a fixed stare.
- His/her mouth may fall open slightly as the jaw relaxes.
- Body fluids (urine or stool) may be released as muscles relax.

**Remember: You do not need to call 911 or the emergency number for your area. Call Capital Caring Health office and ask to speak to a nurse immediately.**

You will be offered a visit from the nurse, but it is not a requirement except in the District of Columbia. In Virginia and Maryland, you may decline the nurse to visit. If you choose to decline, the nurse can contact the funeral home and/or the patient's physician for you.

If you accept a nursing visit, a nurse will come to your home and contact the funeral home and physician. The date and time of death recorded by the nurse will be based on when the nurse arrives and confirms that your loved one has passed.



We are here  
for you. Call us  
day or night,  
**800.869.2136**





## *For caregivers: support for you*

### TAKE CARE OF YOURSELF

Many caregivers become so involved with meeting patients' needs they neglect their own. It is important to take time for yourself to maintain your health and avoid illness. By taking care of yourself, you will be able to continue caring for your loved one. Here are a few tips:

#### GET ENOUGH FOOD AND REST

- Eat at least three times a day.
- If giving care to your loved one disturbs your sleep, take naps and rest when the patient rests.

#### TAKE TIME TO RELAX

- Get outside
- Relax in a warm bath
- Read a book or listen to music
- Let yourself be alone for a short time
- Ask for a Capital Caring Health Volunteer to provide respite care

#### LET OTHERS HELP

- Allow family and friends to participate in the care
- Ask friends to bring meals, run errands, or sit with the patient
- Ask for a Capital Caring Health Volunteer

#### SEEK AND ACCEPT SUPPORT

- Talk to friends and family about your feelings
- Find ways to care for your spiritual self
- Capital Caring Health's Interfaith Chaplains are available to provide spiritual support and help.

You may also want to consider privately hiring additional help to assist you. Your Capital Caring Health hospice team can assist you with a list of resources in your area.

## COMMUNICATING NEEDS & FEELINGS

Often times families do not talk to one another about dying for fear of upsetting them. Your Capital Caring Health Hospice Services care team can help by:

### LISTENING

- Feelings of worry, hurt, anger, love, fear and guilt are all normal

### HELPING YOU FIND WAYS TO TALK WITH EACH OTHER

**TALKING WITH THE PATIENT** when it is too painful for families to hear his or her concerns about the end of life.

- Working through “unfinished business” in patient’s mind
- Offering a neutral professional to develop solutions to issues

## HELP WITH DIFFICULT CHOICES

Decisions about treatment choices can be difficult. The stress of serious illness or approaching death can further complicate decision-making, especially when information seems confusing.

New technologies in medical care present patients, families and professional caregivers with hard choices. These choices may involve artificial nutrition (tube feedings) or hydration, treatment choices and resuscitation questions.

Making such choices may result in ethical challenges for the patient or family. Capital Caring Health upholds the quality of life. If you need help sorting through treatment choices and your feelings about them, Capital Caring Health can help.

Your Capital Caring Health team is trained to help you make choices that are best for you. Our bioethics committee— which includes physicians, nurses, social workers, clergy and community professionals— is available for your consultation. This committee:

- Listens to your concerns and gives you thoughtful feedback
- May make recommendations, or my simply review issues and options with you

- Offers a forum of respect where the ethical, medical, legal, psychosocial, spiritual and administrative issues are addressed along with treatment options.

**To access the Capital Caring Health Bioethics Committee, please speak with your nurse.**

## *Grief and Bereavement Services*

Capital Caring Health helps you through the bereavement process following your loved one’s death. Our team of highly trained and experienced professionals can help you during this difficult time. These services are a part of your hospice benefit- **there is no charge for hospice families.**

You will begin receiving a series of specialized mailings beginning about a month after your loved one’s death. These packets include information about grief along with tools that will enable you to assess your progress along the journey of mourning. They will also include schedules of upcoming grief support events and the name and contact information of our grief counselors.

Between four (4) and eight (8) weeks after the death of your loved one, you will receive a phone call from a bereavement staff member to ask you how you are managing and to discuss our support that is available to you.

Our services include short term grief counseling of up to eight (8) individual sessions during the 13 months following the patient’s death. We hold regularly scheduled drop in support group sessions which you are invited to join at any time. We also invite you to participate in our special workshops and camps addressing specific concerns, such as children’s grief and dealing with holiday grief.

## PLEASE SHARE YOUR FEEDBACK

**About eight (8) weeks after the death of your loved one, you will receive a survey in the mail about the hospice care your loved one received from the Capital Caring Health hospice team. Your feedback is important, and helps us improve our services. Thank you in advance for taking time to complete the survey.**

# PATIENT RIGHTS & RESPONSIBILITIES



# 8 PATIENT RIGHTS & RESPONSIBILITIES

**As a patient receiving care from Capital Caring Health, you have certain rights and responsibilities. Your family, designated durable power of attorney (POA), or guardian may exercise your rights if you are unable to do so.**

## *You have the right to*

- Be informed verbally and in writing of these rights prior to start of care in a language and manner understandable to you.
- Be informed of and receive information about our policies on Advance Directives in accordance with State law; as well as Durable Do Not Resuscitate Order (DNR) information (where applicable) prior to start of services.
- Be advised, before care is initiated, of the extent to which payment for services may be expected from federal or state programs, and the extent to which payment may be required from you; third-party payers; and any other source of funding known to Capital Caring Health Hospice Services.
- Be advised, verbally and in writing, of any changes in fees for services that are your responsibility. Capital Caring Health will advise you of these changes as soon as possible but no later than 30 calendar days from the date we become aware of the change.
- Exercise your rights as a patient of Capital Caring Health without being subjected to discrimination or reprisal for exercising these rights.
- Be treated with courtesy, consideration and respect for your dignity.
- Be free from mistreatment, neglect, or verbal, mental, sexual and physical abuse, including injuries of an unknown source, and misappropriation of your property.
- Choose your personal (attending) physician.
- Voice grievances and complaints to Capital Caring Health, government agencies or accrediting agencies regarding our services, treatment or care by anyone who is furnishing services on behalf of Capital Caring Health without fear of threat or reprisal.
- Receive effective pain and symptom management.
- Be involved in developing your customized Plan of Care, including appropriate assessment.
- Refuse care or treatment or services, including continued participation in our program.
- Be assured the right to privacy.
- Be served by individuals who are properly trained and competent to perform their duties.
- Feel secure regarding confidentiality of your protected health information and any related privacy and security protections mandated by federal law and outlined in our Notice of Privacy Practices.
- Be informed of Capital Caring Health's discharge plans, receiving at least five days' verbal and written notice prior to termination of services.
- Be informed of short-term inpatient care options available for pain control, symptom management, and respite.
- Receive information about services covered under Medicare hospice benefit or by other payers, services we will provide and any limitation(s) to those services, and to be informed of any charges/services not covered by insurance.
- Receive information addressing any beneficial relationship between the organization and referring entities.

## Concerning your medical decisions, you have the right to

- Make decisions about your medical care, including the right to accept or refuse treatment. A federal law called Patient Self Determination Act protects these rights.
- Choose what medical treatment you do or do not want, now or in the future.
- Appoint someone to make your medical decisions for you if, in the future, you cannot make those decisions yourself (called a durable Power of Attorney for Health Care).
- Make sure people know about your decisions. You can simply tell them, or you can put your directions in writing.
- Change your mind at any time.

## You have the responsibility to

Respect the safety of all staff and volunteers involved in your care while they are in your home.

### FOR US TO PROVIDE CARE YOU MUST:\*

- Turn on an outside light when a nurse or other staff member is arriving at night. Keep walkways well-lit and clear of hazards.
- Be sure your address is visible from the street.
- Keep pets under control during staff visits.
- Please honor a care provider's request to put an animal in another room during the visit.
- Remove all guns from the premises prior to Capital Caring Health care providers coming to your home. If this is not possible, make sure that all guns are unloaded, and ammunition is stored separately in a locked location. Also, please ensure that other weapons (knives, etc.) are not readily accessible in your home.
- Ensure all electrical systems and equipment are in good working order and electrical cords and cables are not used where they may be damaged or cause a tripping hazard.
- Observe fire-safety standards, such as removing flammable materials, keeping fire exits clear, installing active smoke detectors.
- Follow all instructions for the safe use of oxygen tanks including **no smoking when oxygen is in use.**
- Minimize the spread of infection by properly disposing of infectious materials and keeping surfaces clean.

**\*If hospice care providers are exposed to unsafe situations, we may reassess whether we can continue to provide our services in that setting. We appreciate your attention to these safety issues and concerns.**

- Notify your neighborhood office if you will not be available at the predetermined visit time.
- Notify your neighborhood office as soon as possible if you are transported to or admitted to a hospital.
- Notify your neighborhood office if you leave the service area or change locations between DC, Maryland and Virginia.
- Speak with our staff in a respectful, nonthreatening manner.
- Provide information that is accurate and complete to the best of your knowledge, about past illness, present complaints, and all other health care-related problems.
- Notify us if your physician orders tests or scans, so that we can coordinate your plan of care.
- Follow the customized Plan of Care determined by you, your physician and the hospice care team.
- Pay for services not fully covered by Medicare, Medicaid or private insurance\*\*

**\*Financial assistance is available, based on federal poverty guidelines. For more information, please speak with a member of your hospice team.**

## *Notice of privacy practices*

This notice describes how medical information about you may be used and disclosed and how you can get access to this information. Please review it carefully.

## *Use and disclosure of health information*

Capital Caring Health (“Hospice”) may use your health information, information that constitutes protected health information as defined in the Privacy Rule of the Administrative Simplification provisions of the Health Insurance Portability and Accountability Act of 1996, for purposes of providing you treatment, obtaining payment for your care and conducting health care operations.

The Hospice has established policies to guard against unnecessary disclosure of your health information.

### **THE FOLLOWING IS A SUMMARY OF THE CIRCUMSTANCES UNDER WHICH AND PURPOSES FOR WHICH YOUR HEALTH INFORMATION MAY BE USED AND DISCLOSED:**

**TO PROVIDE TREATMENT:** Capital Caring Health may use your health information to coordinate care within the Hospice and with others involved in your care, such as your attending physician, members of the Hospice interdisciplinary team and other health care professionals who have agreed to assist the Hospice in coordinating care. For example, physicians involved in your care will need information about your symptoms in order to prescribe appropriate medications. The Hospice also may disclose your health care information to individuals outside of Capital Caring Health involved in your care including family members, clergy who you have designated, pharmacists, suppliers of medical equipment or other health care professionals.

**TO OBTAIN PAYMENT:** Capital Caring Health may include your health information in invoices to collect payment from third parties for the care you receive from CCH. For example, CCH may be required by your health insurer to provide information regarding your health care status so that the insurer will reimburse you or CCH. CCH also may need to obtain prior approval from your insurer and may need to explain to the insurer your need for care and the services that will be provided to you.

**TO CONDUCT HEALTH CARE OPERATIONS:** Capital Caring Health may use and disclose health information for its own operations in order to facilitate the function of CCH and as necessary to provide quality care to all of CCH's patients. Health care operations includes such activities as:

- Quality assessment and improvement activities.
- Activities designed to improve health or reduce health care costs.
- Protocol development, case management and care coordination.
- Contacting health care providers and patients with information about treatment alternatives and other related functions that do not include treatment.
- Professional review and performance evaluation.
- Training programs including those in which students, trainees or practitioners in health care learn under supervision.
- Training of non-health care professionals.
- Accreditation, certification, licensing or credentialing activities.
- Review and auditing, including compliance reviews, medical reviews, legal services and compliance programs.
- Business planning and development including cost management and planning related analyses and formulary development.
- Business management and general administrative activities of the Hospice.
- Fundraising for the benefit of the Hospice.

For example, Capital Caring Health may use your health information to evaluate its staff performance, combine your health information with other patients in evaluating how to more effectively serve all patients, disclose your health information to CCH staff and contracted personnel for training purposes, use your health information to contact you as a reminder regarding a visit to you, or contact you as part of general fundraising and community information mailings (unless you tell us you do not want to be contacted).

Capital Caring Health may disclose certain information about you including your name, your general health status, your religious affiliation and listing you within a CCH directory while you are in a Capital Caring Inpatient Center. CCH may disclose this information to people who ask for you by name. *Please inform us if you do not want your information to be included in the directory.*

**FOR FUNDRAISING ACTIVITIES:** Capital Caring Health and its supporting Foundation may use information about you including your name, address, phone number and the dates you received care in order to contact you or your family to raise money for CCH. CCH may also release this information to a related foundation. *If you do not want Capital Caring Health to contact you or your family, notify the Department of Philanthropy office at 703-538-2066, or write to: Capital Caring Health, Philanthropy Department, 3180 Fairview Park Drive, Falls Church, VA 22042, and indicate that you do not wish to be contacted.*

**FOR APPOINTMENT REMINDERS:** Capital Caring Health may use and disclose your health information to contact you as a reminder that you have an appointment for a home visit.

**FOR TREATMENT ALTERNATIVES:** Capital Caring Health may use and disclose your health information to tell you about or recommend possible treatment options or alternatives that may be of interest to you.



## THE FOLLOWING IS A SUMMARY OF THE CIRCUMSTANCES UNDER WHICH AND PURPOSES FOR WHICH YOUR HEALTH INFORMATION MAY ALSO BE USED AND DISCLOSED.

**WHEN LEGALLY REQUIRED:** Capital Caring Health will disclose your health information when it is required to do so by any federal, state or local law.

**WHEN THERE ARE RISKS TO PUBLIC HEALTH:** Capital Caring Health may disclose your health information for public activities and purposes in order to:

- Prevent or control disease, injury or disability, report disease, injury, vital events such as birth or death and the conduct of public health surveillance, investigations and interventions.
- Report adverse events, product defects, to track products or enable product recalls, repairs and replacements and to conduct post-marketing surveillance and compliance with requirements of the Food and Drug Administration.
- Notify a person who has been exposed to a communicable disease or who may be at risk of contracting or spreading a disease.
- Notify an employer about an individual who is a member of the workforce as legally required.

### **TO REPORT ABUSE, NEGLECT OR DOMESTIC VIOLENCE:**

Capital Caring Health is allowed to notify government authorities if CCH believes a patient is the victim of abuse, neglect or domestic violence. CCH will make this disclosure only when specifically required or authorized by law or when the patient agrees to the disclosure.

### **TO CONDUCT HEALTH OVERSIGHT ACTIVITIES:**

Capital Caring Health may disclose your health information to a health oversight agency for activities including audits, civil administrative or criminal investigations, inspections, licensure or disciplinary action. CCH, however, may not disclose your health information if you are the subject of an investigation and your health information is not directly related to your receipt of health care or public benefits.

**IN CONNECTION WITH JUDICIAL AND ADMINISTRATIVE PROCEEDINGS:** Capital Caring Health may disclose your health information in the course of any judicial or administrative proceeding in response to an order of a court or administrative tribunal as expressly authorized by such order or in response to a subpoena, discovery request or other lawful process, but only when CCH makes reasonable efforts either to notify you about the request or to obtain an order protecting your health information.

**FOR LAW ENFORCEMENT PURPOSES:** As permitted or required by state law, Capital Caring Health may disclose your health information to a law enforcement official for certain law enforcement purposes as follows:

- As required by law for reporting of certain types of wounds or other physical injuries pursuant to the court order, warrant, subpoena or summons or similar process.
- For the purpose of identifying or locating a suspect, fugitive, material witness or missing person.
- Under certain limited circumstances, when you are the victim of a crime.
- To a law enforcement official if the Hospice has a suspicion that your death was the result of criminal conduct including criminal conduct at CCH.
- In an emergency in order to report a crime.
- To monitor your compliance with a condition of pretrial release, probation, parole, supervised release, or diversion agreement regarding mental health treatment.

**TO CORONERS AND MEDICAL EXAMINERS:** Capital Caring Health may disclose your health information to coroners and medical examiners for purposes of determining your cause of death or for other duties, as authorized by law.

**TO FUNERAL DIRECTORS:** Capital Caring Health may disclose your health information to funeral directors consistent with applicable law and if necessary, to carry out their duties with respect to your funeral arrangements. If necessary to carry out their duties, CCH may disclose your health information prior to and in reasonable anticipation of your death.

**FOR ORGAN, EYE OR TISSUE DONATION:** Capital Caring Health may use or disclose your health information to organ procurement organizations or other entities engaged in the procurement, banking or transplantation of organs, eyes or tissue for the purpose of facilitating the donation and transplantation.

**FOR RESEARCH PURPOSES:** Capital Caring Health may, under very select circumstances, use your health information for research. Before CCH discloses any of your health information for such research purposes, the project will be subject to an extensive approval process, including obtaining consent for inclusion in a study.

**IN THE EVENT OF A SERIOUS THREAT TO HEALTH OR SAFETY:** Capital Caring Health may, consistent with applicable law and ethical standards of conduct, disclose your health information CCH, in good faith, believes that such disclosure is necessary to prevent or lessen a serious and imminent threat to your health or safety or to the health and safety of the public.

**FOR SPECIFIED GOVERNMENT FUNCTIONS:** In certain circumstances, the federal regulations authorize Capital Caring Health to use or disclose your health information to facilitate specified government functions relating to military and veterans, national security and intelligence activities, protective services for the President and others, medical suitability determinations and inmates and law enforcement custody.

**FOR WORKER'S COMPENSATION:** Capital Caring Health may release your health information for worker's compensation or similar programs.

**CHESAPEAKE REGIONAL INFORMATION SYSTEM FOR OUR PATIENTS (CRISP):** We have chosen to participate in the Chesapeake Regional Information System for our Patients (CRISP), a regional health information exchange serving Maryland, and D.C. As permitted by law, your health information will be shared with this exchange in order to provide faster access, better coordination of care and assist providers and public health officials in making more information decisions. You may "opt-out" and disable access to your health information available through CRISP by calling 1-877-952-7477 or completing and submitting an Opt-Out form to CRISP by mail, fax or through their website at [www.crisphealth.org](http://www.crisphealth.org). Public health reporting and Controlled Dangerous Substances information, as part of the Maryland Prescription Drug Monitoring Program (PDMP), will still be available to providers.

## AUTHORIZATION TO USE OR DISCLOSE HEALTH INFORMATION

Other than what is stated above, Capital Caring Health will not disclose your health information without your written authorization. If you or your representative authorizes CCH to use or disclose your health information, you may revoke that authorization in writing at any time.

## YOUR RIGHTS WITH RESPECT TO YOUR HEALTH INFORMATION

You have the following rights regarding your health information that Capital Caring Health maintains:

**RIGHT TO REQUEST RESTRICTIONS:** You may request restrictions on certain uses and disclosures of your health information. You have the right to request a limit on CCH's disclosure of your health information to someone who is involved in your care or the payment for your care. However, CCH is not required to agree to your request. We are not required to agree to your request if it is not feasible for us to ensure our compliance or believe it will negatively impact the care we may provide you. To request a restriction, you must make your request in writing to the Privacy Officer, Capital Caring Health, 3180 Fairview Park Drive, Falls Church, VA 22042. In your request, you must tell CCH what information you want to limit and to whom you want the limits to apply.

**RIGHT TO RECEIVE CONFIDENTIAL COMMUNICATIONS:** You have the right to request that CCH communicate with you in a certain way. For example, you may ask that CCH only conduct communications pertaining to your health information with you privately with no other family members present. If you wish to receive confidential communications, please contact the Privacy Officer, Capital Caring Health, 3180 Fairview Park Drive, Falls Church, VA 22042. CCH will not request that you provide any reasons for your request and will attempt to honor your reasonable requests for confidential communications.

## RIGHT TO INSPECT AND COPY YOUR HEALTH

**INFORMATION:** You have the right to inspect and copy your health information, including health and billing records. This does not include psychotherapy notes. A request to inspect and copy records containing your health information may be made in writing to the Privacy Officer, Capital Caring Health, 3180 Fairview Park Drive, Falls Church, VA 22042. If you request a copy of your health information, CCH may charge a reasonable fee for costs associated with copying and assembling your request. We may deny your request to inspect and copy your health information in certain, very limited, circumstances. If you are denied access to health information, you may request that the denial be reviewed. The person conducting the review will not be the person who denied your request, and we will comply with the outcome of the review.

**RIGHT TO AMEND HEALTH CARE INFORMATION:** You or your representative have the right to request that CCH amend your records, if you believe that your health information is incorrect or incomplete. The request may be made as long as the information is maintained by CCH. A request for an amendment of records must be made in writing to the Privacy Officer, Capital Caring Health, 3180 Fairview Park Drive, Falls Church, VA 22042. CCH may deny the request if it is not in writing or does not include a reason for the amendment. The request also may be denied if your health information records were not created by CCH, if the records you are requesting are not part of CCH's records, if the health information you wish to amend is not part of the health information you or your representative are permitted to inspect and copy, or if, in the opinion of CCH, the records containing your health information are accurate and complete.

**RIGHT TO AN ACCOUNTING:** You or your representative have the right to request an accounting of disclosures of your health information made by CCH for certain reasons, including reasons related to public purposes authorized by law and certain research. The request for an accounting must be made in writing to the Privacy Officer, Capital Caring Health, 3180 Fairview Park Drive, Falls Church, VA, 22042. The request should specify the time period for the accounting starting on or after April 14, 2003. Accounting requests may not be made for periods of time in excess of six (6) years. CCH would provide the first accounting you request during any 12-month period without charge. Subsequent accounting requests may be subject to a reasonable cost-based fee.

**RIGHT TO A PAPER COPY OF THIS NOTICE:** You or your representative have a right to a separate paper copy of this Notice at any time even if you or your representative have received this Notice previously. To obtain a separate paper copy, please contact the Privacy Officer at 703-957-1769. You may also obtain a copy of the current version of Capital Caring Health's Notice of Privacy Practices at our website, [www.capitalcaring.org](http://www.capitalcaring.org)

**CRISP:** We participate in the CRISP health information exchange (HE) to share your medical records with your other health care providers and for other limited reasons. You have rights to limit how your medical information is shared. We encourage you to read our Notice of Privacy Practices and find more information about CRISP medical records sharing policies at [www.crisphealth.org](http://www.crisphealth.org).

**MENTAL HEALTH INFORMATION DISCLOSURE AMENDMENT ACT OF 2018 - DC RESIDENTS:** permits the disclosure of mental health information by a third-party payor to a health care provider in certain enumerated instances, to require a health care provider to notify clients whether a third-party payor's privacy practices permit the disclosure of mental health information, and to allow clients to prevent the disclosure of mental health information by a third-party payor upon request.

## *Duties Capital Caring Health*

Capital Caring Health is required by law to maintain the privacy of your health information and to provide to you and your representative this Notice of its duties and privacy practices. CCH is required to abide by the terms of this Notice as may be amended from time to time. CCH reserves the right to change the terms of its Notice and to make the new Notice provisions effective for all health information that it maintains. If CCH changes its Notice, CCH will provide a copy of the revised Notice to you or your appointed representative. You or your personal representative have the right to express complaints to CCH and to the Secretary of DHHS if you or your representative believe that your privacy rights have been violated. Any complaints to CCH should be made in writing to the Privacy Officer, Capital Caring Health, 3180 Fairview Park Drive, Falls Church, VA, 22042. Capital Caring Health encourages you to express any concerns you may have regarding the privacy of your information. You will not be retaliated against in any way for filing a complaint.

### **CONTACT PERSON**

Capital Caring Health has designated the Privacy Officer as its contact person for all issues regarding patient privacy and your rights under the Federal privacy standards. You may contact this person at the Privacy Officer, Capital Caring Health, 3180 Fairview Park Drive, Falls Church, VA, 22042, telephone number 703-957-1769.

**EFFECTIVE DATE:** This Notice is effective February 21, 2022.

# NOTES

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# HOW TO COMMUNICATE A CONCERN OR COMPLIMENT





# 9 HOW TO COMMUNICATE A CONCERN OR COMPLIMENT

## *How to Communicate a Concern or Compliment*

Capital Caring Health Hospice Services' goal is to provide you with support of the highest quality. To accomplish this goal, we have a Quality Assessment and Performance Improvement Program that monitors your satisfaction with our care and continually seeks ways to improve.

If you have a concern or compliment regarding any aspect of your care from Capital Caring Health Hospice Services, you may first wish to discuss it with your nurse or your social worker. However, you are welcome and invited to contact us directly. Please call our Office of Organizational Performance at 703-712-4874.

Capital Caring Health Hospice Services also is accredited by Community Healthcare Accreditation Program (CHAP), to which you can submit a concern toll-free at 1-800-656-9656.

Other resources to help you resolve problems include **The Home Care Ombudsman**. This program provides free services concerning the rights of home care consumers to residents of their respective communities. Numbers for Home Care Ombudsman programs in Virginia, the District of Columbia, and Maryland:

### **NORTHERN VIRGINIA**

703-324-5411

*(for residents of Alexandria, Arlington, Fairfax, Fauquier, Loudoun, Prince William, and Stafford counties)*

### **DISTRICT OF COLUMBIA**

202-434-2190

### **PRINCE GEORGE'S COUNTY, MD**

301-265-8483

There are state and district offices at which you may voice a grievance or ask questions pertaining to home-delivered care. In Virginia, call the **Office of Licensure and Certification at 800-955-1819**, Monday through Friday, 8 a.m. to 5 p.m. This number may be used to register complaints pertaining to hospice care or Advance Directive requirements. At times, an answering machine will record your message. The office is at 9960 Maryland Drive, Suite 401, Henrico, VA 23233-1463.

Additionally, in Virginia, you can call the office of the **State Long-Term Care Ombudsman Virginia Association of Area Agencies on Aging (V4A) at 1-800-552-3402 or 804-565-1600**, Monday through Friday, 8:30 am to 5 pm. The office is located at 24 East Cary Street, Suite 100, Richmond, VA 23219.

To submit a complaint in Maryland, patients can call the **Maryland State Office of Health Care Quality's Home Health Hotline at 1-800-492-6005**. The Hotline's hours of operation are Monday through Friday 8:30 a.m. to 5 p.m. After hours, you may leave a voice mail message and your call will be returned. The office is at Spring Grove Hospital Center, Bland Bryant Building, 55 Wade Avenue, Catonsville, MD 21228.

District of Columbia residents may contact the **DC Department of Health Licensing and Regulatory Administration at 202-442-5833**. Their office hours are Monday through Friday, from 8:30 a.m. to 4:30 p.m., after which there is a recorded message. Their office is located at DC Department of Health, 825 N. Capitol St. NE, Washington DC, 20002.

You can also call 1-800-MEDICARE. TTY users should call 1-877-486-2048. Visit [www.medicare.gov](http://www.medicare.gov) for more information.

# WAYS TO GIVE



*There are many ways to support Capital Caring Health's work and help us to simply improve care to those facing life-limiting illness and their families.*

We serve nearly 1,200 hospice patients every day and rely upon the community for millions of dollars each year for such critical programs as our Patient Care Fund that allows us to serve everyone, regardless of their resources, as well as bereavement support, and four inpatient centers.

So often we hear words of appreciation from families and friends who had a loved one in our care. They ask, "What can I do to give back?" Capital Caring Health has many ways to show gratitude and support our services, and we're happy to work with you to make your gift as meaningful as possible.

For over 40 years, we've been a vital part of your community. We hope you'll join us and be a part of ours.

**DONATE:** Financial contributions help us to help others. Your donation will help ensure that everyone who needs our services receives our support, regardless of their ability to pay, for years to come. We accept Visa, MasterCard, Discover, and American Express.

- **Online:** Make a secure gift to Capital Caring Health online at [www.capitalcaring.org](http://www.capitalcaring.org). You can make your gift in memory of or in honor of a loved one.
- **Phone:** Call us at 703-531-2380. A Philanthropy representative is available to assist you.
- **Mail:** Mail gifts to Capital Caring Health, Philanthropy, 3180 Fairview Park Dr., Headquarters/Suite 500, Falls Church, VA 22042.

**IN HONOR, IN MEMORY OR IN LIEU OF FLOWERS** Honor someone important in your life. We acknowledge each gift to the donor and we send a letter to the family with a list of family and friends who made memorial gifts. Dollar amounts are never included. To suggest donations in lieu of flowers, simply mention us in the obituary with this or similar language: Memorial donations may be made to Capital Caring Health, Philanthropy, 3180 Fairview Park Dr., Headquarters/Suite 500, Falls Church, VA 22042.

**CONSIDER A MEMORIAL NAMING OPPORTUNITY.** Capital Caring Health offers several physical ways to memorialize a loved one, including: bricks and pavers, artwork, patient rooms and offices, and outdoor gardens and furniture. Let us help you create a meaningful and lasting tribute.

**MONTHLY GIVING:** Join other "Circle of Caring" members by becoming a monthly donor and provide consistent, reliable and unrestricted financial support. Indicate this selection when you make your donation online or by mail, using a credit or debit card.



**PLANNED GIVING:** Planned gifts, no matter the size, have the power to change lives for generations to come. You can become a Heritage Society member by providing for Capital Caring Health in your estate plans or through a life-income gift. Whatever your financial circumstances or charitable goals, we'll show you how you can make a gift that benefits you and your loved ones, as well as our mission.

**WORKPLACE GIVING:** Workplace-giving programs such as the Combined Federal Campaign (CFC) and Combined Virginia Campaign (CVC) allow employees to give through a federal government agency, Virginia state agency, or cooperating corporation by designating Capital Caring Health as their workplace giving beneficiary. CFC #39664. Combined Virginia Campaign #0416.

**EVENTS:** Each year, Capital Caring Health hosts several fundraising events that support a variety of programs and services, including our Passion for Caring Gala, Hospice Comes to Washington, Hospice Cup sailing regatta, and more. We also help individuals host events in their home or place of business, giving us an opportunity to share the value of our services with friends, neighbors, and colleagues.

**DONATE BY SHOPPING:** Donate items to and/or shop at our Thrift Store located at 6172 Arlington Blvd. in Falls Church. All proceeds from the stores support Capital Caring Health programs.



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

**AMAZON SMILE:** Amazon Smile is a simple and automatic way for you to support Capital Caring Health, every time you shop – at no cost to you. Search [www.smile.amazon.com](http://www.smile.amazon.com), select “Capital Hospice” as the beneficiary and a portion of your purchases will be donated to Capital Caring Health.

**DONATE A VEHICLE:** We make car donations easy! Arrange for free pickup or towing of your vehicle and you receive a tax deduction. Capital Caring Health is registered with v-Dac. v-Dac accepts any vehicle. There is no cost to the donor or to Capital Caring Health. For more information: [www.v-dac.com](http://www.v-dac.com).

## CORPORATE PARTNERSHIP PROGRAM

Our Corporate Partnership Program provides exclusive benefits to corporate and business supporters. The program revolves around an annual fundraising events and networking calendar. Businesses meet corporate social responsibility goals while promoting their businesses to Capital Caring Health supporters.

*Capital Caring Health is registered as a 501(c)3 nonprofit organization and contributions are tax-deductible to the extent permitted by law.*

*Please be assured that Capital Caring Health does not sell or share donor information with third parties.*

# ABOUT CAPITAL CARING HEALTH

Capital Caring Health's Mission is to provide patients and their families with advanced illness care of the highest quality. Since 1977, Capital Caring Health has simply improved care for those facing life-limiting illness through direct support of patients and their families, public education and advocacy. Since its inception, Capital Caring Health has provided hospice, palliative care, and counseling to nearly 120,000 patients and their families.

To learn more about Capital Caring Health, visit [www.capitalcaring.org](http://www.capitalcaring.org) or call 800-869-2136.

## NOTICE OF NON-DISCRIMINATION

### CARING FOR ONE AND ALL

Capital Caring Health does not exclude people or treat them differently for any reason, including but not limited to: sexual orientation, gender identity, gender expression, religion, diagnosis or medical condition, veteran status, ancestry, marital status, occupation, pregnancy, citizenship, political affiliation, or source of payment.

Capital Caring Health respects the belief system of its patients and their families, and does not impose any belief system on its patients or their families.

Capital Caring Health provides free aids and services to people with disabilities to communicate effectively with us. Capital Caring Health also provides free language services to people whose primary language is not English. If you need these services, please let our staff know of your need for effective communication.

If you believe that Capital Caring Health has failed to provide these services or discriminated in another way on the basis of race, color, national origin, age, disability, gender identity, sex, or any of the above categories, you can file a grievance with:

Chief Performance & Compliance Officer  
Capital Caring Health  
3180 Fairview Park Dr., Suite 500  
Falls Church, VA 22042

[cpc@capitalcaring.org](mailto:cpc@capitalcaring.org)

You may file a grievance in person, by mail, or email. If you need help filing a grievance, you may call a Capital Caring Health team member at 703-712-4874 for assistance.

You may also file a civil rights complaint with the U.S. Department of Health and Human Services, Office for Civil Rights, electronically through the Office for Civil Rights Complaint Portal, available at <https://ocrportal.hhs.gov/ocr/portal/lobby.jsf>, or by mail or phone at:

U.S. Department of Health and Human Services  
200 Independence Avenue, SW  
Room 509F, HHH Building  
Washington, D.C. 20201

1-800-368-1019, 800-537-7697 (TDD)

Complaint forms are available at <http://www.hhs.gov/ocr/office/file/index.html>.





# CARE FORMS



# 11 CARE FORMS

*available on the following pages*

# WOUND CARE INSTRUCTIONS FOR FAMILIES & CAREGIVERS

*Dear Caregiver,*

The plan of care for your loved one includes care of a wound. We want to make sure you have clear instructions regarding the treatment and have all the information you need. If you have any questions or concerns, **please call your Capital Caring Health Team.**

| WOUND #1: LOCATION               | WOUND #2: LOCATION               | WOUND #3: LOCATION               |
|----------------------------------|----------------------------------|----------------------------------|
| <i>Clean with</i>                | <i>Clean with</i>                | <i>Clean with</i>                |
| <i>Place on/in wound</i>         | <i>Place on/in wound</i>         | <i>Place on/in wound</i>         |
| <i>Protect/ cover with</i>       | <i>Protect/ cover with</i>       | <i>Protect/ cover with</i>       |
| <i>Dressing change frequency</i> | <i>Dressing change frequency</i> | <i>Dressing change frequency</i> |
| <i>Call the office if :</i>      | <i>Call the office if w:</i>     | <i>Call the office if :</i>      |
| <i>Other comments</i>            | <i>Other comments</i>            | <i>Other comments</i>            |

# QUESTIONS TO ASK CAPITAL CARING HEALTH STAFF

*Patient's Name*

| QUESTION | ANSWER |  |
|----------|--------|--|
|----------|--------|--|

\_\_\_\_\_

*date*

\_\_\_\_\_

*name of person you asked*

\_\_\_\_\_

*date*

\_\_\_\_\_

*name of person you asked*

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*name of person you asked*

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*date*

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*name of person you asked*

# SIGN IN: CAPITAL CARING HEALTH STAFF VISITS

| DATE/TIME | NAME/DISCIPLINE | DATE OF NEXT VISIT EXPECTED | WHO IS EXPECTED AT NEXT VISIT? (DISCIPLINE) |
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|-----------|-----------------|-----------------------------|---|

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# PAIN DIARY

Patient's Name \_\_\_\_\_

## USE THESE CODES TO COMPLETE THIS FORM

### TREATMENT

RX= Medication

R= Repositioned

M= Music

MAS= Massage

O= Other

I= Ice

D= Distraction

S= Spiritual (prayer)

### EFFECT

+ = Good result

- = No result

| DATE | TIME | PAIN SCORE (0-10) | DESCRIPTION OF PAIN | TREATMENT | EFFECT | PAIN SCORE AFTER TREATMENT (0-10) | TIME |
|------|------|-------------------|---------------------|-----------|--------|-----------------------------------|------|
|------|------|-------------------|---------------------|-----------|--------|-----------------------------------|------|

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# PATIENT MEDICATION LIST

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*Patient's Name*

## CURRENT MEDICATIONS

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# APPENDIX



## CAPITAL HOSPICE POLICY & PROCEDURE

MEDICATION – MANAGEMENT

POLICY NUMBER: PC.M50

**Regulatory Citation/Other:** 42 CFR 418.106(a); Maryland DHMH Hospice Care Program 10.07.21.15.C; Maryland DHMH Medical Care Program 10.09.35.06.B(6); Virginia Licensure of Hospice 12VAC5-391-190-C(7); 12VAC5-391-430; 12VAC5-391-460; Virginia DMAS Manual Chapter VI

**CHAP:**

**Original Date:** 12/08 **Reviewed:** 9/12 **Revised:** 8/15, 12/18

**Board Approval:** 12/17/12

**Implemented:** 1/18/13

**Policy Owner:** Pharmacy and Therapeutics Committee

### POLICY STATEMENT

To provide a frame work for managing medications in the home care environment that is consistent with applicable Federal and State laws and accepted standards of hospice care.

- *related and no longer helpful* – medications in this category are documented with justification why in the patient’s record OR
- *clearly unrelated* – medications in this category are documented with justification why in the patient’s record.

### PROCEDURES

#### A. MANAGEMENT OF MEDICATIONS

1. The IDG confers with the Hospice Medical Doctor (HMD) who has education and training in drug management to ensure that drugs and biologicals meet each patient’s needs.
2. The HMD regularly reviews patient medications and determines based on the patient’s terminal diagnosis and secondary diagnoses, goals of care, current condition, and level of care what medications are:

3. When a medication is determined to be:
  - *Related and still helpful:* Capital Hospice is responsible for coverage
  - *Related but no longer helpful:* the patient and family will be responsible for payment through their pharmacy; should there be a Part D plan it will be notified that the patient is responsible.
  - *Clearly unrelated:* depending on the medication; the payment will come from available source(s) such as Part D plan, third party payer, or patient.

- *related and still helpful;*

4. Conversations with the patient and family regarding medications occur as often as appropriate throughout the course of care.
  5. Medications are provided on a timely basis and are available twenty-four (24) hours a day and seven (7) days a week, as needed.
  6. All medications are ordered by a licensed physician or nurse practitioner in accordance with the patient's plan of care and State law.
  7. A *Medication Profile* is maintained for every patient by the nurse case manager or designee. It includes a listing of the current medications ordered for each patient and specifies coverage responsibilities.
  8. Medication errors and adverse drug reactions receive immediate response and are documented and reviewed to ensure corrective action is taken to prevent future occurrences.
  9. The hospice nurse evaluates the patient/caregiver's ability to safely administer medications, and provides instruction to the patient/caregiver regarding:
    - The proper storage, handling and preparation of medications,
    - The safe administration of medications,
    - Potential side effects and expected responses to prescribed medications.
  10. The patient/caregiver(s) are educated about and agree:
    - To administer medications according to their prescribed doses and ranges;
    - Not to adjust medications doses on their own, but to contact the hospice nurse or designee if the medication(s) are not working.
    - Prescribed medications will only be used by the hospice patient.
  11. Medication is only administered by persons who have authority to do so under State laws and regulations.
  12. Medications are dispensed in enough quantities to meet the needs of the patient and to minimize the potential for waste.
  13. Each visit, the Hospice Nurse, or designee, reconciles the medications dispensed to and used by the patient. This may include counting to ensure that proper quantities are available and that the medications are taken as prescribed.
  14. If there is a concern that medications are missing, the Hospice Nurse, or designee will assist the patient/caregiver in:
    - Determining the amount of medication missing
    - Attempting to locate the medications
    - Determining where and when the medication loss may have occurred.
  15. In the event of suspected or actual diversion of controlled substances, the Hospice Nurse or designee will inform their Clinical Supervisor and follow policy PC.M70 Medication Diversion.
- B. DISPOSAL OF MEDICATIONS**
16. At the time of admission to hospice, the Capital Caring Health employee obtaining the consent:
    - Provides a copy of the Capital Hospice written policies and procedures on the management and disposal of controlled drugs to the patient or patient representative and family; (PC.M50; PC.M60)
    - Discusses the hospice's policies and procedures for managing the safe use and disposal of controlled drugs with the patient or representative and the family in a language and manner that they understand to ensure that these parties are educated regarding the safe use and disposal of controlled drugs; and
    - Documents in the patient's clinical record that the written policies and procedures for managing controlled drugs were provided and discussed.
  17. The Hospice Nurse in collaboration with the patient's attending physician, if any, and/or the Hospice Medical Doctor, will determine if a discontinued medication should be retained for possible future patient use and will instruct the patient/family on safe storage. Medications that are no longer needed are disposed of in accordance with accepted standards of practice.

**Regulatory Citation/Other:** 418.106(e)(2); HR.6-54 Chapter 3 Section 3221-3222; Maryland Bill 232; Virginia 32.1-162.5:1; 54.1-3441.2

**CHAP:** HCDT 35.D

**Original Date:** 10/18 **Revised:** 8/19

## PURPOSE

To provide a safe disposal procedure of a patient's unused prescription medication(s) for patients residing at home at the time of their death; when the prescription has been discontinued by a prescriber or the prescription has expired.

For patients residing in assisted living facilities (ALFs) or nursing homes (NHs) medication disposal will be performed by the facility.

## DEFINITIONS

**SECOND CAPITAL HOSPICE EMPLOYEE:** is defined as a licensed nurse, social worker, hospice physician, nurse practitioner, physician's assistant or hospice aide.

## GUIDELINES

1. The disposal can be performed by a licensed nurse, physician's assistant, or physician.
2. Staff will be trained in how to use the Capital Caring Health provided medication disposal product.
3. Disposal of medications will occur on-site at the patient's home using an approved method of disposal. Medications are **not** to be removed from the residence under any circumstances.
4. The hospice employee will discuss disposal of medications with the patient, the patient's family member or personal representative.
5. The employee will have the patient, the patient's family member or personal representative sign the *Prescription Medication Reconciliation* form either authorizing or refusing that the employee dispose of the medications.

## AUTHORIZED COLLECTION AND DISPOSAL

6. Disposal of medications by a Capital Caring Health employee will be witnessed by:
  - Patient, patient's family member or personal representative. OR
  - Second Capital Hospice Employee, OR
  - A local law enforcement officer (in Maryland only)
7. The medication collection and disposal will be documented in the patients record, on the *Prescription Medication Reconciliation* (MR.M7) form including:
  - The date and time;
  - Prescription medication name(s), dosage and quantity;
  - The name of the individual and relationship who authorized the collection and disposal;
  - The name of the Capital Hospice employee who collected and disposed of the prescription medications;
  - The name of the witness to the collection and disposal if different than the individual authorizing.

## DECLINED COLLECTION AND DISPOSAL

8. In the event the witness declines the counting of medication(s) by the Capital Hospice Employee, the employee will document *DEFERRED* in the count column of the medication(s).
9. *The Prescription Medication Reconciliation* will be turned into Medical Records and scanned into the patient's electronic medical record.
10. Documented in the patient's record on the *Prescription Medication Reconciliation* form:
  - The date
  - Prescription medication name(s) and quantity
  - That the individual declining the collection and disposal of the prescription medications has been instructed in the proper disposal.

## OTHER CIRCUMSTANCES

11. In the event a patient dies at home and the family declines a visit by a hospice nurse, the Triage staff will request that the family/caregiver destroy the medications. This instruction will be documented in the patient's electronic medical record.
12. If a patient is transferred to a Capital Hospice inpatient facility and dies there, the inpatient unit staff will request that family destroy any patient medications that were left at home.
13. In the event medications are not able to be located at the time of death, the nurse should document "Medications Not Located" on the form and have a person present sign the form.
14. If there are complicating circumstances such as paramedics present at the time of death, the nurse will document in the electronic medical record the circumstances and that medication disposal was unable to be performed. The nurse case manager or designee will attempt to contact the family to instruct in medication disposal the next business day.



**See Page 3** for  
How to contact  
Capital Caring  
Health



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

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24-HOUR CARE LINE

**(888) 325-1239**