



Your Compassionate Guide,  
helping you *live better.*



**Patient & Caregiver  
Resource Guide**

Patient Priority Line 904.407.7300  
877.699.7300 toll free

## IMPORTANT NAMES & NUMBERS

Your Community Hospice team is available 24 hours a day, 7 days a week.  
If an emergency occurs, your first instinct may be to call 911.

***Before you call 911 or decide to go to a hospital, please call  
Community Hospice of Northeast Florida.***

### **24/7 PATIENT PRIORITY LINE**

**904.407.7300**

**877.699.7300 toll free**

**Always call Community Hospice first.**

#### **Please notify Community Hospice of Northeast Florida:**

- When patient's condition changes, or patient becomes restless or agitated
- About patient and family questions or concerns
- Before transfer to home, hospital or nursing home
- If death occurs

### **Your Patient Care Team**

Community Hospice Patient Security Code: \_\_\_\_\_

Team Name: \_\_\_\_\_

Team Physician or Advanced Registered Nurse Practitioner (ARNP):  
\_\_\_\_\_

Primary Nurse: \_\_\_\_\_

Psychosocial Specialist: \_\_\_\_\_

Chaplain: \_\_\_\_\_

Hospice Aide/Certified Nursing Assistant (CNA):  
\_\_\_\_\_

Team Manager: \_\_\_\_\_

## MISSION

To improve the quality of life for patients and families, and to be the  
Compassionate Guide® for end-of-life care in our community.

## VISION

To be the provider of choice and leader in our community  
for innovative solutions in end-of-life care.

## VALUES

Integrity • Leadership • Ownership • Teamwork  
Superior Service • Respect and Value for the Individual



Dear Patient and Family,

Thank you for selecting Community Hospice of Northeast Florida for your care during this important time in your lives. We are honored by the trust you have shown in allowing us the privilege of serving you and your family.

Since 1979, Community Hospice has provided compassionate support to people with advanced illness. Our goal is to provide high-quality programs and services that are helpful to you and those who are caring for you.

This guide is designed to provide information about our care and to address frequently asked questions and concerns. We have learned that when our patients and their families first come under our care, many find themselves dealing with an overwhelming amount of information, along with the need to make critical decisions during a time of significant stress.

All of us at Community Hospice are here to help. We hope this guide addresses many of your initial questions and provides other important information to assist in meeting your care needs. In this guide, we touch on some end-of-life care concerns, such as dealing with pain or discomfort, financial coverage for care, safety issues, advance directives, patient care and emotional support for the patient, family and caregiver. Information also may be found in the *For Patients & Families* section of our website, **CommunityHospice.com**.

We are here for you—to guide and support you and your family during this difficult time. If you have any questions or concerns, please contact your care team manager listed on the first page of this guide. You also may call our 24/7 Patient Priority Line at **904.407.7300** (877.699.7300 toll free) day or night.

Sincerely,

Susan Ponder-Stansel  
President and Chief Executive Officer



# PATIENT AND CAREGIVER RESOURCE GUIDE

## TABLE OF CONTENTS

Important Names & Numbers .....	1
Mission & Vision .....	2
Letter from President & CEO .....	3
<b>Welcome</b>	
Community Hospice of Northeast Florida Program .....	9
Hospice Care .....	9
Grief and Loss Support .....	9
Developing Your Plan of Care .....	10
Patients' Rights and Responsibilities .....	11
Community Hospice Notice of Privacy Practices .....	11
How Community Hospice Protects Your Health Information .....	11
Your Rights to Access and to Control the Use and Disclosure of Your Health Information .....	13
Requests for Restrictions on Health Information, Questions or Complaints .....	14
Use and Disclosure of Your Health Information Without Your Authorization .....	15
Revisions of this Notice .....	17
Community Hospice Patient and Family Rights and Responsibilities Guidelines .....	17
<b>Hospice Services</b>	
About Community Hospice Care .....	19
Your Community Hospice Team .....	20
Physician or Advanced Registered Nurse Practitioner .....	20
Nurse .....	20
Psychosocial Specialist .....	21
Chaplain .....	21
Certified Nursing Assistant (CNA) .....	21
Volunteer .....	21
Bereavement Counselor .....	22
Complementary Therapy Services .....	22
Levels of Care .....	22
Routine Home Care .....	22
Respite Care .....	22
Crisis Intervention Care .....	22
Inpatient Care .....	23
Who Pays for Hospice Care? .....	23
Medicare Hospice Benefit .....	23
Medicare Summary Notice .....	23
Medicaid Hospice Benefit .....	24
Reporting Medicaid Fraud .....	24
Private Insurance Coverage .....	25
Uninsured Care .....	25
<b>Patient Care</b>	
Calling the 24/7 Patient Priority Line (904.407.7300) .....	27
Managing Symptoms.....	27

Agitation.....	28
Bleeding.....	28
Breathing Care .....	29
Confusion .....	31
Constipation/Diarrhea.....	32
Difficulty Swallowing.....	34
Dry Mouth .....	34
Fatigue .....	35
Fluid Retention.....	36
Gastrostomy or Feeding Tube Care .....	36
Preparing Medications for Gastrostomy or Feeding Tube .....	37
Cleaning the Tube and Giving the Food or Medications .....	37
Gurgling or Rattling Breathing.....	38
Insomnia.....	38
Itching .....	39
Nausea/Vomiting.....	40
Seizures .....	41
Sweating.....	42
Urine Elimination .....	43
Urinary Catheter Care/Irrigation.....	43
Food and Water:A Hospice Perspective .....	45
Adding Calories.....	46
Recipes.....	48
More Ways to Add Calories.....	50
Caregiver Tips.....	52
Bathing .....	52
Mouth Care.....	53
Skin Care .....	53
Moving the Patient (Transfer).....	54
Assisting the Patient From Sitting to the Standing Position.....	55
Helping Patient Move From Bed to Chair,Wheelchair or Bedside Commode.....	55
Assisting the Patient with Walking .....	56
Using a Walker or Cane.....	56
Using a Shower Chair or Bath Bench.....	56
Placing a Lift Sheet.....	57
Uses for a Lift Sheet.....	57
Changing Sheets with a Patient in the Bed .....	58
Placing a Patient on a Bedpan .....	59
Infection Control .....	60
How to Properly Wash Your Hands .....	60
Safety in the Home.....	61
Fire Safety.....	61
Falls Prevention .....	62
Emergency Preparedness.....	64
Evacuation Checklist.....	65
Loss of Telephone/Communications.....	66
Loss of Power.....	67
Disaster Planning Resources.....	67

## **Medication & Pain Management**

Calling the 24/7 Patient Priority Line (904.407.7300) .....	69
Recognizing and Managing Pain .....	69
Pain Management Assessment.....	71
Responsive Patient – Use Numeric Pain Rating Scale.....	71
Post-Intervention: Patient Verbal Response .....	71
Numeric Pain Rating Scale .....	71
Impaired or Non-Responsive Patient .....	71
Direct Staff Observation.....	71
FRAAC Pain Rating Scale .....	72
Post-Intervention: Cognitively Impaired/Non-Responsive .....	73
Treatment of Pain .....	73
Taking Your Pain Medications .....	74
Non-Drug Treatment of Pain .....	74
Medications.....	74
Receiving Your Medications .....	75
Taking Your Medications Safely .....	75
Comfort Care Kit.....	76
Morphine Liquid Concentrate .....	76
Rectal Medications .....	77
Community Hospice Policies for Medication Management and Destruction.....	77
Policy—Medication Management for Patients Residing at Home.....	77
Policy—Destruction of Patient Medications in the Home .....	80
Procedure .....	80

## **Medical Equipment**

Medical Equipment and Supplies.....	83
Home Oxygen Therapy .....	83
General Rules About Oxygen in the Home .....	84
Oxygen Concentrator.....	84
Safety Instructions for the Oxygen Concentrator .....	84
Care and Maintenance of the Oxygen Concentrator.....	85
How to Operate the Oxygen Concentrator .....	85
What to Do When the Oxygen Concentrator is Not Working.....	86
Oxygen Concentrator Troubleshooting.....	86
Oxygen Cylinder (Tank).....	88
Safety Instructions for the Oxygen Cylinder (tank).....	88
Turning on Portable Oxygen System .....	88
To Replace the Oxygen Cylinder (tank) .....	88
Oxygen Cylinder (Tank) Troubleshooting.....	89
Nebulizer .....	90
To Set up Nebulizer .....	90
To Clean the Nebulizer Cup .....	90
Nebulizer Troubleshooting.....	91
Durable Medical Equipment (DME) Troubleshooting Guide.....	92
Hospital Bed .....	92
Hospital Bed Troubleshooting.....	93

Overbed Table .....	94
Bedside Commode.....	94
Wheelchair.....	95
Walker .....	95
Bath and Shower Chair .....	95
<b>What To Expect</b>	
Changing Care Location .....	97
Transferring to an Inpatient Hospice Center for Caring .....	97
Transferring from Home to an Assisted Living or Long-Term Care Facility.....	97
Caring for the Caregiver .....	98
Your Family May Also Need Help .....	98
The Stress of Caring Too Much.....	99
Avoiding Compassion Fatigue.....	99
Relaxation Techniques .....	100
Saying Good-Bye .....	100
The Last Stages.....	101
Signs and Symptoms of Approaching Death.....	102
<b>Advance Care Planning &amp; Planning Ahead</b>	
About Advance Care Planning .....	105
The Patient's Right to Decide.....	105
Statement of Advance Directives or Living Wills .....	106
Community Hospice Policy on Advance Directives and Advance Care Planning.....	107
Types of Advance Care Planning Documents .....	107
Honoring Choices® Florida Advance Care Plan .....	107
About Do Not Resuscitate (DNR) Orders .....	109
Deciding About Advance Care Planning .....	110
When Making a Decision about an Advance Care Plan .....	110
If You Complete an Advance Care Plan.....	110
If You Already Have an Advance Care Plan .....	111
If You Want to Consider Having a DNR Order .....	111
Organ, Tissue and Full Body Donation .....	111
Final Arrangements: Plan Ahead .....	112
Funeral Services .....	112
Burial .....	112
Cremation .....	112
Burial at Sea .....	113
Funeral Home Selection Checklist.....	113
The Memorial Service .....	114
Handling Financial and Legal Tasks .....	114
Administrative Tasks.....	115
Helpful Reminders .....	116
Financial Considerations .....	117
<b>Forms and Logs</b>	
Designation of Health Care Proxy.....	119
Informed Consent.....	121



Patient/Family Election Statement.....	123
Florida Medicaid Hospice Care Services Election Statement.....	125
Facility Agreement.....	127
Explanation of General Inpatient Care at Inpatient Care Centers.....	129
Medication Log .....	131
Pain Control Diary .....	137
Patient Instruction Sheet.....	139
Don't Forget to Ask About .....	141

# COMMUNITY HOSPICE OF NORTHEAST FLORIDA PROGRAM

Community Hospice of Northeast Florida is the first and only community-based, nonprofit palliative and hospice care provider that offers a full range of programs and services to patients with advanced illness and their families throughout Baker, Clay, Duval, Nassau and St. Johns counties.

## **Hospice Care**

The goal of hospice care is to enable you to be alert and pain-free... to live each day as fully as possible, wherever you may live. Medicare, Medicaid and private insurance cover the cost of care, however care is provided regardless of ability to pay. Hospice care consists of the following:

- Support to you and your loved ones with a diagnosis of an advanced illness and a prognosis of 12 months or less of life expectancy (six months or less for Medicare eligibility)
- A focus on comfort and quality of life, rather than a cure
- Experienced interdisciplinary team of physicians, nurses, certified nursing assistants, specialized wound care nurses, psychosocial specialists, chaplains, volunteers, complementary therapy (massage, music, occupational, physical and respiratory) staff and bereavement counselors supports the patient, caregiver and family members, as needed and documented in the individualized plan of care
- Physical, emotional and spiritual support for patient, caregiver and family

## **Grief and Loss Support**

Community Hospice offers grief and loss services for those who have experienced the death of a loved one and who may need support or guidance in dealing with their sorrow. Services are available for anyone in the community and include:

- Individual and family counseling, including children and teens
- Therapeutic grief support groups
- *Understanding Grief* – a program for the newly bereaved
- Annual candlelight service of remembrance in December
- *Hope for the Holidays* program to cope with grief during this time of year

## DEVELOPING YOUR PLAN OF CARE

The first few days of receiving hospice care may seem very busy as you meet with members of your Community Hospice care team and begin to receive medications, supplies and medical equipment to address your needs.

In most cases, your plan of care has already been started by an admissions nurse who has explained our services and ordered initial medications, supplies and equipment. Next, you will meet with your primary team nurse who will work with you and your caregivers to continue to develop your **personalized plan of care**.

Your plan of care is essential to ensuring that you, your family and your care team are working together to meet your specific care goals. Your plan of care (or care plan) will guide everyone to ensure the entire team supports your unique needs and provides you and your family an excellent experience.

You also will meet with a psychosocial specialist—a highly trained hospice social worker/counselor—who will provide additional resources as needed, as well as a chaplain who is available for spiritual guidance.

We are here for you anytime you need us—day or night, every day of the week. Just **call the 24/7 Patient Priority Line at 904.407.7300** (877.699.7300 toll free) to speak with a clinical staff member who can assist you over the phone or send someone to you, if needed.

After the first few days with Community Hospice, your care plan will become easier to understand and your care easier to manage. During this time, it is critical that you communicate with your team. Let them know what you are experiencing and ask questions.

Hospice care can be a transition, but your Community Hospice team is available to provide caring support for you and your family.

## PATIENTS' RIGHTS AND RESPONSIBILITIES

We notify you in writing of your rights and responsibilities before your care begins. Consistent with state laws, your family and/or guardian may exercise your rights if/when you are unable to do so. Community Hospice has an obligation to protect and promote your rights and the rights of all patients.

Likewise, you have certain responsibilities while under Community Hospice care. Federal and state law require that we recognize your rights while you are receiving medical care from us and that you respect our right to expect certain behaviors from you.

### ***Community Hospice Notice of Privacy Practices (effective March 1, 2016)***

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

Community Hospice creates and maintains a medical record in paper and electronic formats for the purpose of documenting the care provided to you and your family.

The personal, financial and protected health information in your medical record (collectively, "Health Information") includes your medical, mental, family, and social histories, descriptions of medical treatment by Community Hospice and other health care providers, and personal and financial information which could be used to identify you.

This Notice of Privacy Practices ("Notice") describes Community Hospice's responsibility to protect the privacy of your Health Information and your rights, under federal and state law, to control your Health Information.

### ***How Community Hospice Protects Your Health Information***

Community Hospice is required, by law and the terms of this Notice, to:

- 1) Protect the privacy and security of the Health Information which Community Hospice acquires from and about you;



- 2) Notify you in the event the privacy or security of your Health Information is breached; and
- 3) Provide a paper copy of this Notice to you.

Additionally, whenever Community Hospice is authorized, permitted or required to provide your Health Information to another person or entity, Community Hospice endeavors to provide only the minimum information necessary to comply with the request (*for example, Community Hospice provides only that amount, type or category of information specifically requested and does not provide any other information*).

Community Hospice contracts with third parties to perform record keeping and other records services that may require access by those contractors to your Health Information. Community Hospice requires those contractors to execute a Business Associate Agreement. The Business Associate Agreement requires the contractor to comply with applicable privacy and security standards and laws.

Community Hospice does not disclose, sell or give your Health Information to any person or entity who intends to use, or will use, it for marketing or selling goods or services to you.

Community Hospice allows the Community Hospice of Northeast Florida Foundation for Caring, Inc. a not-for-profit fundraising foundation, access to patient and family contact information for the limited purpose of soliciting donations and volunteers for Community Hospice. Community Hospice of Northeast Florida Foundation for Caring, Inc. correspondence always includes instructions for how you and your family may opt-out of future foundation fundraising communications.

Community Hospice will retain your Health Information for five years after you are discharged from Community Hospice. Your Health Information, unless subject to a pending request from a governmental authority or court order, will then be destroyed in a manner that will render it unrecognizable. If you are not 18 years of age or older upon discharge, your Health Information will be retained for five years plus the number of years remaining until you reach age 18.

Unless during your life you (or your lawful representative) expressly state in writing that a specific person or entity is authorized after your death to request your Health

Information, then a court order may be required pursuant to Florida Statute Section 400.611(3) before Community Hospice will release your records.

The Community Hospice medical record containing your Health Information is a single multidisciplinary record. Community Hospice does not create or maintain psychotherapy notes or substance abuse treatment records. The multidisciplinary record may contain substance abuse or mental health information incidental to developing a hospice plan of care. These types of Health Information will be included in Community Hospice's response to an otherwise lawful request for your complete medical record unless you specifically and timely advise us in writing that you do not want specified information disclosed.

### ***Your Rights to Access and to Control the Use and Disclosure of Your Health Information***

You have the right, by submitting a written request to Community Hospice, to:

- 1) **inspect, obtain a copy of, and correct your Health Information** *(Community Hospice will respond to you or your lawful representative within 30 days of your request, and will charge a reasonable, cost-based fee for copying);*
- 2) **receive communications regarding your Health Information in the manner you choose** *(for example, you may specify that you only want to be contacted at a specific email address, telephone number or street address, or request only an electronic copy of your Health Information);*
- 3) **receive an accounting of all disclosures (but not all uses) of your Health Information** *(Community Hospice may collect a reasonable cost-based fee for preparing a requested accounting);*
- 4) **receive a paper copy of this Notice**, even if you have received an electronic copy;
- 5) **request a restriction on disclosure of your Health Information to a health plan** *(if you or someone on your behalf, other than the health plan, pay in full the charges due for your hospice care, then Community Hospice will implement the requested restriction);*

- 6) **request any other limitation or restriction on access and use of your Health Information.** Your request will be implemented by Community Hospice unless the request is one prohibited by law, or unless the circumstances would not allow Community Hospice to agree to your request (*for example, you may request that your medical record contents or some specific portion of the record not be shared with a particular person or entity and, unless applicable law or circumstances prohibit it, Community Hospice will implement your request*);
- 7) **designate another person to receive a copy of your Health Information** by making and signing a written designation which clearly identifies your designee and where the copy should be sent;
- 8) **object to being included in a directory of patients and restrict the disclosure of general information regarding your current condition as a patient, your current location and contact information;** and
- 9) **make a complaint**, if you believe Community Hospice has violated your right to privacy under the terms of this Notice or under federal or state law. Community Hospice is prohibited by law from retaliating against you for filing a complaint. Your complaint may be filed with Community Hospice, the Secretary of Health and Human Services or Florida Attorney General.

### ***Requests for Restrictions on Health Information, Questions or Complaints***

You may request copies of your Health Information, place restrictions on the disclosure and use of your Health Information or submit a question or a complaint regarding your rights under the terms of this Notice, to Community Hospice:

Community Hospice of Northeast Florida, Inc.  
ATTN: Privacy Officer/VP of Compliance and Quality/Chief Compliance Officer  
4266 Sunbeam Road  
Jacksonville, Florida 32257  
904.407.7087

You also may submit a complaint regarding your rights under the terms of this Notice to:

The U.S. Department of Health & Human Services  
Hubert H. Humphrey Building  
200 Independence Avenue, S.W.  
Washington, DC 20201  
Toll Free Call Center: 1-877-696-6775

Or

Office of Attorney General  
State of Florida  
The Capitol PL-01  
Tallahassee, FL 32399-1050  
Florida Toll Free: 1-866-966-7226

### ***Use and Disclosure of Your Health Information Without Your Authorization***

Federal and state law allow Community Hospice to use and disclose your Health Information without your prior authorization, in order to:

- 1) **provide hospice treatment and care to you and your family, including disclosing your protected health, personal and financial information to other health care professionals who are treating you** *(for example, giving a home health aide your home address and clinical information so that he/she can provide care in your home);*
- 2) **conduct routine health care operations at Community Hospice** *(for example, using your clinical information to evaluate the quality of care and develop best practices at Community Hospice); and*
- 3) **bill for the services we provide to you** *(for example, using your personal and financial identifying data to receive payment from Medicare, health insurance plans or other payors who may be responsible to pay for all or part of the care Community Hospice provides to you).*



Community Hospice may, without your authorization, also be required to disclose some or all of your Health Information in order to:

- 4) **comply with a law that requires disclosure;**
- 5) **respond to requests from public health authorities and agencies conducting health oversight activities;**
- 6) **help prevent the spread of disease;**
- 7) **participate in a recall of medical devices or medications;**
- 8) **report suspected abuse, neglect or domestic violence to proper authorities;**
- 9) **when deemed reasonably necessary, to prevent a serious threat to anyone's safety or health;**
- 10) **participate in properly approved research;**
- 11) **respond to court orders, lawful administrative orders, certain subpoenas and investigative requests from federal and state regulators or law enforcement authorities** *(for example, if a court enters an order requiring the disclosure of the contents of your medical record to third parties);*
- 12) **respond to tissue and/or organ donation requests** *(for example, if you are an organ donor, Community Hospice can disclose clinical information to the organ or tissue bank);*
- 13) **respond to requests from medical examiners and funeral directors;**
- 14) **participate in lawsuits or legal actions involving your Health Information;** and
- 15) **respond to requests from law enforcement officials and requests involving workers' compensation claims.**

### ***Revisions of this Notice***

Community Hospice reserves the right to revise the terms of this Notice. If Community Hospice materially changes the terms of this Notice, it will post a copy of the revised Notice on our website **CommunityHospice.com**. The first use and effective date of this Notice is March 1, 2016.

## **COMMUNITY HOSPICE PATIENT AND FAMILY RIGHTS AND RESPONSIBILITIES GUIDELINES**

As a Community Hospice patient, family member or caregiver, you have certain rights and responsibilities, including:

- Exercising your rights as a patient of our program without discrimination on the basis of race, religion, age, gender, national origin, sexual orientation, marital status, disability, veteran status, diagnosis, cost of therapy, ability to pay or life circumstances.
- Being involved in developing your or your family member's hospice plan of care.
- Making informed decisions regarding care or services.
- Accepting or refusing care or treatment and being informed of potential results and/or risks.
- Formulating advance directives at the individual's option.
- Having complaints heard and reviewed.
- Confidentiality in accordance with state and federal regulations.
- Having your property and person treated with respect.
- Receiving effective pain management and symptom control for conditions related to the hospice diagnosis.
- Choosing your or your family member's attending physician.
- Being free from mistreatment, neglect, or verbal, mental, sexual and physical abuse, including injuries of unknown source.

To report a complaint regarding your patient rights or the services you receive, **please call 904.407.7097.**



## ABOUT COMMUNITY HOSPICE CARE

Community Hospice programs and services are designed for people facing a life-limiting illness who choose to focus on comfort and quality of life, rather than a cure. The goal of hospice care is to help people, like you or your loved one, live each day as fully as possible.

Community Hospice care is provided by an interdisciplinary team that focuses on delivering expert medical care, pain and symptom management, and emotional and spiritual support. This care is tailored to your needs and wishes, and supports your family and caregivers. Anyone whose illness is expected to limit his or her life to 12 months or less is eligible for hospice care.

Community Hospice care is usually provided at home, wherever that may be in the five counties of Northeast Florida (Baker, Clay, Duval, Nassau and St. Johns), including assisted living and skilled nursing facilities. Some patients may need more care for a short period and will come to one of our inpatient care centers, which are conveniently located throughout the First Coast.

Community Hospice will develop a plan of care for you based on your wishes and needs. You and your caregiver are part of the care planning team and will be asked for input. The team will discuss all aspects of the care plan to ensure that everyone is in agreement.

Sometimes you or your family member may wish to seek additional medical care or hospital services. If there is interest in these services, we recommend discussing them with your team or calling the Community Hospice 24/7 Patient Priority Line for pre-authorization before seeking care (including calling 911).

If you elect to receive medical care or hospice services without pre-authorization, you may either self-pay for the service or revoke hospice services. Medicare pays Community Hospice directly at a specified daily rate for all care provided. The team delivers care based on your plan of care and remains involved to determine if the services are related to your terminal diagnosis.

Community Hospice provides services to residents in skilled nursing and assisted living facilities. When we take care of patients in one of these facilities, we work with the primary caregivers and medical staff in each facility. Our goal is to develop a collaborative plan of care that will maximize the services provided.



## YOUR COMMUNITY HOSPICE TEAM

Your Community Hospice team includes you, your family and caregiver, your physician, Community Hospice physician or advanced registered nurse practitioner (ARNP), primary nurse (RN), certified nursing assistant (CNA), psychosocial specialist and chaplain. The team also may include volunteers, complementary therapy staff, bereavement counselors and other medical professionals as needed. Each team member brings special skills and expertise to provide care specially tailored to meet the needs and wishes of you and your family.

Your team meets regularly to discuss your plan of care, including any concerns you or your family may have. If your condition improves over time, then you, the team and your doctor may decide you no longer need hospice care. You would be discharged from services for a period until you decline from your illness.

Your **Community Hospice physician or ARNP** and your own physician work together on your treatment. Your Community Hospice nurse will discuss your plan of care, receiving directions and orders for your care, treatment and medications from either doctor. The team will communicate with your physician regularly and provide updates on your condition. The Community Hospice physician will work to keep you comfortable and manage any urgent medical symptoms or pain.

Your **Community Hospice nurse** is educated specifically in caring for patients with progressive, incurable illnesses. Your nurse is there to be your Compassionate Guide® to help you understand what is happening and what to expect in the days and/or weeks ahead. He or she teaches “hands-on” caregiving skills needed for your care and comfort to allow your caregivers to feel confident in their abilities to support a seriously ill patient. Your nurse or another nurse on your patient care team will continually evaluate your pain and any other symptoms, monitoring any changes in your condition and letting you know what to expect as your illness progresses.

Your **Community Hospice psychosocial specialist** is professionally trained as a social worker or counselor. He or she can help you and your family cope with the stress, grief and other issues associated with your illness. Your psychosocial specialist will provide counseling, assist with financial concerns, advance care planning, caregiving arrangements, make referrals to other community agencies as needed and/or just be there to listen.

Your **Community Hospice chaplain** respects and seeks to honor your personal spiritual practices and faith/belief system preferences. Respecting your wishes, chaplains are available to provide whatever measure of spiritual support our patients and their caregivers desire. In addition to theological education, Community Hospice chaplains have training in geriatrics and the social sciences. Therefore, our chaplains are well equipped to listen to and discuss any spiritual or religious concerns you want to address. If you are affiliated with an area faith community and your pastor, priest, rabbi, imam or other faith representatives are contacting you regularly, our chaplains are honored to partner with them to provide any additional spiritual care you may desire. If you are not connected with a local faith group, chaplains are available to serve as your spiritual resource or contact leadership of your faith/belief preference if you wish. When requested, your chaplain can assist you and your family with funeral plans and memorial remembrances. If you just simply would like a caring, interested person with whom to visit, our chaplains are skilled listeners with supportive spirits who consider it a privilege to journey along with you.

Your **Community Hospice certified nursing assistant (CNA)** is licensed by the state to assist with personal care and activities of daily living (ADLs), such as bathing, hair care, shaving, skin care, changing bed linens, and helping to maintain a clean and safe environment.

Your **Community Hospice volunteer** has received extensive training to support you and your family. Volunteers may be available on a regular basis or a one-time request. A volunteer may stay with you for a couple of hours, offer companionship or emotional support, run an errand or pick up needed supplies. Your team members can give you more information and request a volunteer for you.

Your **Community Hospice bereavement counselor** is a licensed mental health professional who provides bereavement care to family members following the patient's death. The bereavement team offers grief and loss support and help with finding ways to cope.

In addition, Community Hospice offers **complementary therapy services** as needed such as massage, music, occupational, pet, physical and respiratory therapy. These therapies treat the entire person—mind, body and spirit—and can provide the patient with many benefits, including relaxation, decreased pain, better response to medications, more restful sleep, reduced anxiety and an overall sense of calm.

## LEVELS OF CARE

### ***Routine Home Care***

Most of our Community Hospice patients will receive routine home care. If you are living in your private residence, a nursing home/skilled nursing facility or assisted living facility, your care needs will be managed by the Community Hospice team.

### ***Respite Care***

Caregivers sometimes need a break from providing constant care, so Community Hospice offers respite care. While the caregiver is taking an extended rest, you will be relocated to a skilled nursing facility or one of our inpatient care centers. Respite care is scheduled for up to five days at a time, and can occur more than once.

If you are interested in respite care, contact your psychosocial specialist or primary nurse; they can discuss your needs and arrange for this service.

### ***Crisis Intervention Care (CIC)***

Some patients need more intensive care because pain or other symptoms cannot be controlled or managed at home with routine care. There are two options for a higher level of care; your primary nurse and hospice physician or ARNP will help guide you to the best option.

One option is crisis intervention care (CIC). CIC is provided by a specialized hospice team that will come to your home or facility for short-term management of uncontrolled symptoms. This level of care typically lasts a day or two and will be

evaluated daily by your primary nurse and hospice physician. Once your physician determines that the level of care is no longer necessary, routine home care will continue.

### ***Inpatient Level Care***

A second option is for patients with intensive care needs to come to one of our inpatient hospice Centers for Caring for round-the-clock medical care. You will stay until your condition and symptoms are stabilized, typically three to five days. You will receive intensive nursing, psychosocial support and physician care to alleviate the situation before returning home.

Each Community Hospice Center for Caring features private rooms in a homelike setting where family, friends and loved ones, even pets, can visit day or night.

We know most patients prefer to be cared for at home, so the goal of inpatient care is to return you to your residence as soon as possible. It is not a substitute for home care or long-term care. When your condition stabilizes, with symptoms under control, and the Community Hospice physician determines that the inpatient level care is no longer necessary, you will be transferred from the inpatient care center to an appropriate place of care. Your Community Hospice psychosocial specialist will assist you with a transfer plan that meets your care needs.

*See back cover for Community Hospice inpatient care center locations.*

## **WHO PAYS FOR HOSPICE CARE?**

### ***Medicare Hospice Benefit***

Medicare provides a special program for patients needing hospice care who have a life expectancy of six months or less. These services are delivered to hospice patients—wherever the patient calls home—by a Medicare-certified hospice program. Community Hospice is certified by Medicare to provide these services. The program covers medical services, medications, supplies and equipment that are needed as documented in your plan of care for the hospice diagnosis.

### ***Medicare Summary Notice***

On a quarterly basis, Medicare patients will receive from the Centers for Medicare & Medicaid Services (CMS) a Medicare Summary Notice that lists Medicare health insurance claims information and all the services and supplies billed to Medicare for a 90-day period—for both hospice and non-hospice claims.

The Medicare Summary Notice is not a bill. Hospice care is an “all-inclusive” benefit; you do not owe any money for any of the hospice care provided to you by Community Hospice.

You are not responsible for any difference between the non-covered charges and Medicare’s reimbursement to Community Hospice.

Community Hospice understands that your Medicare Summary Notice may raise questions. Again, the notice is not a bill, and you do not owe any money for the hospice care being provided to you.

We are available to help you understand your Medicare or insurance coverage as it relates to our hospice care. If you have any questions, please call 904.268.5200 and ask to speak with someone in our Finance Department.

### ***Medicaid Hospice Benefit***

Some patients may meet the financial eligibility requirements for reimbursement under Florida Hospice Medicaid. Medicaid provides coverage as defined by the Medicaid Benefit. Your Medicaid card will be used to confirm your eligibility for this benefit. We can assist you in determining and applying for Medicaid eligibility.

If you currently have Medicaid or become Medicaid-eligible, you have a responsibility to report suspected Medicaid fraud. **Please call toll-free 888.419.3456.**

***Medicaid fraud*** is an intentional deception or misrepresentation made by a person with the knowledge that the deception could result in some unauthorized benefit to himself or herself or some other person. It includes any act that constitutes fraud under applicable federal or state law as it relates to Medicaid. The Office of the Inspector General at the Agency for Healthcare Administration accepts complaints regarding suspected fraud and abuse in the Florida Medicaid system by phone at **888.419.3456** or on the agency website at **[http://ahca.myflorida.com/Executive/Inspector\\_General/medicaid.shtml](http://ahca.myflorida.com/Executive/Inspector_General/medicaid.shtml)**.

***Private Insurance Coverage***

Most private insurance plans have a hospice benefit. A member of the Community Hospice team will discuss how insurance benefits are accessed and the specific coverage that you have. In some situations, the hospice benefits provided by insurance companies have requirements based on their individual plans.

Community Hospice will work directly with you and your insurance company to maximize care and services.

***Uninsured Care***

As a nonprofit, mission-driven organization, we are committed to improving the quality of life for all in need of our care throughout Northeast Florida. Through our Community Hospice Foundation, we receive donations from generous supporters in the community for unfunded and under-funded care and services. No one is ever denied care due to an inability to pay.



## PATIENT PRIORITY LINE

***Call the 24/7 Patient Priority Line anytime—  
904.407.7300, 877.699.7300 (toll free)***

We are always available to assist you—24 hours a day, 7 days a week, 365 days a year.

Questions, concerns or problems can often occur during the night or on weekends. Be assured that Community Hospice nursing and/or medical staff is always available through our **24/7 Patient Priority Line** at **904.407.7300**. The staff will help you over the phone or come to your home if needed. Please do not hesitate or wait to call with a question or concern.

When you call, please have your patient security code number ready so the nurse on the phone can easily access your information and plan of care. Your patient number is located on the first page of this guide.

If you call and reach voice mail, please state your patient number, your name and the reason for your call. We will promptly call you back. Do not use your phone while waiting for our return call, and if you haven't heard from us within 15 minutes, please call back.

## MANAGING SYMPTOMS

Caring for a seriously ill loved one at home can be challenging, yet that is where most people want to spend their last days. This section will give you information and tools to help you confidently provide care and alleviate common symptoms that may arise near the end of life.



## **Agitation**

A patient who is agitated usually feels a distressing state of intense restlessness. As a caregiver, you may notice the patient has a short attention span with changes in ability to think clearly.

Several things can cause agitation, including not being able to empty the bladder, constipation, dehydration, shortness of breath, pain, fever, chemical imbalance, or withdrawal from alcohol or nicotine (if there has been a history of such addictions).

If the patient suddenly becomes agitated, call the Community Hospice 24/7 Patient Priority Line. The team will work to find the cause of the agitation so that treatment can begin. Many causes of agitation are difficult to reverse. While it may not be eliminated, agitation still can be decreased with medication and other calming techniques.

The best treatment for agitation usually includes several approaches, only one of which is medication. The things you can do to help relieve agitation include:

- Creating orderly, calm surroundings; reduce excess noise and lights; remove excess blankets.
- Softly playing favorite, soothing music.
- Using a fan to increase the flow of air around the patient, if he/she seems to be having trouble getting enough air.
- Making sure bedclothes are dry.
- Having calm, familiar family members or friends present.
- Gently reminding the patient where he/she is and who is there.
- Not correcting or contradicting the patient if he/she finds it distressing.
- Helping the patient change positions to promote comfort.
- Giving medications that the nurse has instructed you to use for agitation.

**CALL the 24/7 Patient Priority Line with any questions or concerns.**

## **Bleeding**

Some patients may be more likely to bleed because of their illness, so make sure you discuss any issues with your Community Hospice nurse.

Here are some guidelines to prevent bleeding issues:

- Avoid sharp objects.
- Wear slippers or shoes when out of bed.
- Move furniture out of the way. Turn on lights.
- Blow nose gently.
- Clean teeth with a soft toothbrush, sponge toothpaste or washcloth; floss carefully.
- Use an electric shaver.
- Avoid injections if possible.
- Give rectal medicine carefully and with a generous amount of lubricant.
- If bleeding is anticipated, arrange to have dark towels and/or sheets available so blood is less obvious.

***If bleeding occurs, apply pressure if possible and call the 24/7 Patient Priority Line—904.407.7300.***

Report any of the following to your Community Hospice nurse:

- Blood in the urine, stool, sputum or vomit
- Black stools
- Vomit that is dark brown or bright red
- Bloody nose (one that won't stop bleeding)
- Multiple bruises
- Many small, reddish-purple dots under the skin

### **Breathing Care**

Breathing problems can include shortness of breath and gurgling or rattling sounds.

Lung disease, pneumonia and fluid in the lungs may make it difficult to breathe easily. Problems include chest pain, wheezing, a pale or blue skin color, sweating, a fast pulse or fast breathing rate. When a patient has shortness of breath, he/she may become anxious or frightened, which can make the problem seem worse.

As the caregiver, you must remain calm and reassuring. Help the patient be aware of the breathing process and guide him/her to slow down and breathe calmly and deeply.

Using oxygen is not always helpful. Discuss its use with your physician or Community Hospice nurse. Sometimes lungs are so damaged that the extra oxygen can't be absorbed. Also, the use of oxygen can dry out a patient's nose, mouth and throat. Some patients may become more anxious with oxygen tubing on their face.

*What to do:*

- Remain calm and reassuring—this is VERY important.
- Move the patient to a 45-degree angle by raising the head of the bed or using pillows.
- Encourage the patient to gently breathe in through the nose, and then purse the lips, as if whistling, when breathing out. Try not to let the cheeks puff out.
- Try to make sure each breath is slow and deep.
- If using oxygen, be sure that the tubing is not kinking and all connections are tight.
- Set the air conditioner to lower humidity if you can. Also consider using a fan. It is easier to breathe in a cooler room.
- Take medications, if ordered.
- Play music softly and encourage the patient to relax shoulders, back and arms.
- Try to refocus the patient's attention with distractions such as TV, books or other things of interest.
- Keep the number of people in the room to a minimum.
- Keep the patient facing the door or window.

If there is no relief after five minutes, have the patient sit on the bed with feet resting on a stool, arms resting on an over-bed table and head tilted slightly forward.

If the patient is coughing and spitting, note the amount of sputum and what it looks and smells like (normal sputum is clear, white or foamy).

**Call the 24/7 Patient Priority Line—904.407.7300:**

- If the patient's shortness of breath continues
- If the patient spits up thick, yellow, green or bloody sputum
- If the patient's skin is pale or blue, or it feels cold and clammy
- If the patient has a fever
- If the patient is wheezing

## **Confusion**

A patient who is confused has trouble understanding and reacting or responding to his or her environment. It is difficult for the patient to think and act with normal speed and clarity. As a caregiver, this can be challenging at times. Think about the great job you are doing and be confident in your abilities.

Confusion can be caused by:

- Normal illness progression
- Not enough oxygen to the brain
- Tumors
- High fever
- Intense pain
- Some medications
- Unfamiliar surroundings

Some suggestions to help with confusion:

- Always identify yourself.
- Stay within a few feet of the patient while talking. If appropriate, touch the patient during conversation.
- Face the patient when you speak. Talk slowly and use short statements. Avoid speaking loudly.
- Ask if you can turn off the TV or radio during conversations, or play soft, soothing music.
- Remind the patient of the day/date and time and other important information. Keep a clock and calendar nearby. Familiar objects may also be helpful.
- Explain step by step anything you will be doing, such as dressing, bathing or changing bed linens.
- Provide comfortable lighting.
- Notice eating habits. If the patient forgets to eat or chew, he or she may need gentle prompting.

To help with safety:

- Don't leave the patient alone for long periods.
- Help the patient go to the bathroom or to another room.
- Label commonly used items with pictures. For example, place a picture of a flame over the stove.

- Have a written medication schedule and record nearby so it is clear when to take medicines.
- Avoid leaving medications within reach of the patient.

**CALL the 24/7 Patient Priority Line at 904.407.7300 if you notice any of the following:**

- The confusion begins suddenly or worsens
- The patient becomes violent
- Injury occurs

### ***Constipation/Diarrhea***

Constipation or “being bound up” is a change in normal bowel movements that are:

- Less frequent
- Smaller, drier and harder
- Difficult to pass

There are many causes of constipation, including decreased activity, decreased food and fluid intake, illness and some medications.

*What you can do:*

- Administer laxative or stool softener as prescribed.
- Try warm prune juice or other fruit juices.
- Increase the amount of water.
- Increase activity.
- Eat more fresh fruits and fresh vegetables (especially raw and leafy types).
- Increase fiber in your diet by eating more whole wheat or bran cereals and breads.

Diarrhea is frequent, liquid bowel movements with or without discomfort. This happens because the water in the intestine is not absorbed into the body.

*The most common causes are:*

- Medication or laxatives
- Infection
- Tumors

- A blockage of stool in the rectum (an impaction)
- Side effects from chemotherapy or radiation

*If the patient is suffering from diarrhea, it may help to:*

- Stop the use of laxatives and stool softeners.
- Serve food that is high in protein and low in fiber such as cottage cheese, baked potatoes, boiled white rice, cooked cereal, bananas, strawberries, pasta, white toast, apple sauce and yogurt.
- Offer clear liquids, and encourage the patient to drink more frequently.
- Add nutmeg to food; it will slow down the intestines.
- Have the patient rest.
- Offer frequent small meals instead of large meals.
- Place a waterproof bed pad under the patient.
- After each loose stool, clean the rectal area thoroughly with mild soap and water, dry well and apply lotion or water-repellent ointment.

If diarrhea lasts more than 48 hours, make sure the patient drinks only liquids until the diarrhea subsides.

*Also avoid the following:*

- Caffeinated or alcoholic beverages
- Milk/milk products
- Very hot/very cold liquids
- Tobacco products

**Call the 24/7 Patient Priority Line at 904.407.7300 or speak with your nurse if the following occurs:**

- Diarrhea lasts for more than two days and is frequent
- Diarrhea happens three to four times within a few hours
- Blood is in the stool
- Cramping
- Bloating
- Change from constipation to diarrhea
- Fever more than 101 degrees that is not responding to acetaminophen (e.g., Tylenol®)

## **Difficulty Swallowing**

Swallowing can be difficult when the body is weak. Sometimes coughing and choking occur when eating or drinking. This also can make taking medications difficult.

You may notice the following signs:

- Coughing during or right after eating.
- A wet, raspy or gurgling-sounding voice during or after eating or drinking.
- Pain when trying to swallow.
- Food or liquid getting pocketed or stuck in the mouth or leaking from the mouth.

What you can do to assist swallowing:

- Have the patient sit up in bed or in a chair while taking food or liquids.
- Before taking food or medicine, try drinking small sips of water.
- If choking is a problem, tilt head forward during swallowing.
- Thicker liquids are sometimes easier to swallow. Milk shakes or adding gelatin to liquids may help (see nutrition advice in *About Adding Calories* under *Food and Water: A Hospice Perspective* in the *Patient Care* section of this guide).
- A blender may be used to puree foods. Other soft foods such as puddings, mashed potatoes, applesauce or flavored gelatin are good (see nutrition advice in the adding calories and recipes sections).
- Some medicines can be crushed and taken with soft foods to make swallowing easier. Please check with your nurse before crushing medicines since some medicines should not be crushed. Some medicines may be offered in liquid, gel or suppository form if swallowing is difficult.
- If the patient is coughing or choking, don't panic. Turn the patient on his/her side or sit him/her more upright. Do not slap the patient on the back.

**CALL the 24/7 Patient Priority Line at 904.407.7300** or talk with your nurse if you have any questions or concerns.

## **Dry Mouth**

Dry mouth can be caused by mouth breathing, oxygen therapy, poor mouth care, a side effect of medications or a complication of radiation therapy.

Ways to treat dry mouth:

- Encourage sucking on candy, ice chips, popsicles or drinking small sips of water.
- Keep lips moist.
- Do not use mouthwash containing alcohol since the alcohol has a tendency to increase the sensation of dryness.

**CALL the 24/7 Patient Priority Line at 904.407.7300** or talk with your nurse if mouth sores, sore throat or other issues arise.

### **Fatigue**

Fatigue is common among hospice patients. They typically have little energy to do the things they want to do, and resting may not always relieve the fatigue. This kind of fatigue can be as distressing as pain, nausea, vomiting or depression. It can vary in its unpleasantness, severity and the amount of time it is present. Likewise it can be overwhelming and hinder the ability to feel well or enjoy spending time with friends and family.

Other effects from fatigue may include:

- A decrease in the ability to continue normal activities of daily living
- Difficulty in following the plan of care

Many things can contribute to or cause the feeling of fatigue, including low blood counts, medical treatments or interventions, pain and emotional distress, medicines, poor nutrition and/or inactivity.

To help reduce the patient's fatigue you may:

- Help him/her rank activities according to how important they are and when he/she has the most energy.
- Encourage the patient to ask for help and allow others to do some of his/her tasks.
- Place things that are used often within easy reach to save energy.
- Establish a routine.
- Use methods to reduce stress, such as deep breathing, visual imagery, meditation, prayer, talking with others, reading, listening to music, painting or any other activity that is comforting and pleasurable.
- Balance rest and activities. Schedule activities so there is time for plenty of



rest that does not interfere with nighttime sleep. Shorter rest periods often are better than one long one.

- Talk with your Community Hospice nurse about how to manage pain, nausea and depression.
- Ensure the patient eats a balanced diet that includes protein and fluids as he/she can tolerate them.

### **Fluid Retention**

Patients often retain fluid in their legs, ankles, feet, hands and other places. This is called edema (eh-DEEM-a).

Some common causes include:

- A weaker heart
- Less activity
- Pressure from tumors
- Less protein in the diet

Your physician or nurse may be able to give you more information about what is causing the edema.

There are several things you can do to help relieve fluid build-up:

- Elevate the affected areas above the heart if possible, or as able.
- Avoid tight clothing, belts, socks, rings or shoes.
- Avoid salt.
- Be as active as possible; your nurse can demonstrate a few exercises for those who are unable to get out of bed.
- Your physician may prescribe a “water pill” or diuretic, which can help eliminate excess water.

### **Gastrostomy or Feeding Tube Care**

Often gastrostomy or feeding tubes are used for nutrition. It is necessary to understand the proper care of the feeding tube. Your nurse will teach you how to clear the feeding tube after use.

*To use and care for the feeding tube:*

- Wash your hands.
- Gather supplies, including gloves, a funnel, a large syringe, warm water, tablespoon, measuring cup, and prepared food or medication.

*Checking the tube position and residual:*

- Look for a mark on the tube where it should exit the body. If you can't see the mark or if you see more tube below than usual, call the 24/7 Patient Priority Line before trying to administer feedings or medicine through the tube.
- If the tube is correctly positioned, put on your gloves and remove the plug from the end of the tube.
- Insert the syringe in the end of the tube and unclamp the tube.
- Assess how much gastric fluid is in the stomach by pulling back the plunger of the syringe, measure the amount and record, then put gastric fluid back into the stomach. (If there is more than 100 ml do not give feeding.)
- If the patient complains of feeling too full after feedings or experiences regurgitation, stop the feeding and call the 24/7 Patient Priority Line.

***Preparing Medications for Gastrostomy or Feeding Tube***

If liquid medication is not available, you may need to crush the pills or tablets so they can go through the tube; contact your nurse who can assist you.

**Note:** Extended-release or time-release pills MAY NOT be crushed. If you have these types of medications, **call the 24/7 Patient Priority Line at 904.407.7300** or speak with your primary nurse.

Most pills can be crushed with a mortar and a pestle or a pill crusher that your nurse can provide. Crush them into a powder, dissolve the powder in two tablespoons of warm water and pour into the funnel or syringe without a plunger.

**Important:** Never mix medications together. Each medication must be separately poured into the syringe or funnel, followed by a flush.

***Clearing the Tube and Giving the Food or Medications:***

- Raise the head of the bed.
- Measure the feeding using a measuring cup.
- Unplug and insert the funnel or syringe into the opening of the tube (if you are using a syringe, remove the plunger or bulb).

- Pour two tablespoons of water into the funnel or syringe.
- Unclamp the tube and let the water flow into the stomach by gravity.
- If the water flows easily, slowly begin pouring small amounts of food or medication into the tube and continue until all the food or medication is given.
- Once completed, pour two ounces of water into the funnel or syringe as a final flush to clear the tube.
- Re-clamp the tube and remove the funnel or syringe.
- Replace the plug on the end of the tube.
- Wash the funnel or syringe thoroughly.
- Remove gloves and wash hands.
- Keep the patient's head elevated for at least one hour.

### ***Gurgling or Rattling Breathing***

Often during the last days of life, people may be too weak to clear secretions or drainage in the airway. Air moving through these secretions can cause a rattling sound that is sometimes called the “death rattle.”

Although these sounds may be upsetting to others, the patient is usually not aware that it is happening. The gurgling or rattling does not cause distress. Breathing may become irregular and there may be pauses between breaths.

Knowing what to expect and what you can do may help you feel more comfortable and confident:

- Keep the head of the bed raised as this may help the patient breathe easier.
- Turn the patient from one side to the other every 2-3 hours so secretions can drain.
- Keep the patient as comfortable as possible.
- Clean the patient's mouth as needed—contact your nurse if you need mouth swabs.
- Do not try to force the patient to swallow fluids.
- Discuss with your nurse or call the 24/7 Patient Priority Line for help with any breathing issue or question.

### ***Insomnia***

Sleeplessness lowers pain tolerance and exhausts the patient and caregiver. Insomnia may occur because of pain, sweating, coughing, itching, anxiety, depression or the side effects of treatment. Insomnia is common, but here is what you can do to help:

- Don't ignore pain; give medications as prescribed.

- Sometimes simple remedies such as lighter blankets or a nightlight can help.
- Sleep when tired or feeling sleepy. When awake and able, participate in activities and other interests.
- Have someone read aloud.
- Drink warm milk.
- Rest at the same times each day.
- Take medications if prescribed to help sleep or relax.
- Rub the back or massage the feet.
- Keep bed linens clean, neatly tucked in and free of wrinkles.
- Use relaxation techniques.
- Avoid caffeinated beverages (coffee, tea, soda).
- Avoid chocolate.

Discuss sleeping issues and insomnia with your Community Hospice nurse or **call the 24/7 Patient Priority Line.**

### ***Itching***

Itching is an unpleasant sensation of the skin, causing you to scratch or rub. Itching can result in restlessness, anxiety, skin sores and infection. Common causes include dry skin, toxins in the blood, allergy, side effects of medications, chemotherapy, radiation therapy and tumor growth.

#### *What to do:*

- Use soothing over-the-counter lotions, especially after a bath when the skin is damp.
- Use warm instead of hot water for bathing.
- Add baking soda or bath oil to the patient's bath water.
- Wash skin gently using a mild soap. Oatmeal soap is often found to be soothing.
- Thoroughly dry skin and keep it dry. Damp skin, especially in skin folds, can become infected if skin is broken during scratching.
- Treat infected or broken skin with a medicated lotion or powder prescribed by your physician.
- Use baking soda instead of deodorant.
- Keep patient's nails clean and cut short; cover hands with cotton socks or cloth gloves.

- Encourage the patient to wear loose clothing made of a soft fabric.
- Change bed sheets often.
- Keep room cool (60-70 degrees) and well ventilated.
- Have patient drink as much water and other fluids as possible.
- Provide diversions like television, radio or books.
- Administer medications for itching as ordered by the physician.

*Avoid:*

- Scrubbing the skin
- Using a lot of bed covers
- Using harsh detergents
- Using scented and alcohol-based products on the skin
- Drinking alcohol and coffee

If itching continues for more than two days, gets worse, or if hives, welts or open sores develop, discuss what you can do with your Community Hospice nurse or **call the 24/7 Patient Priority Line—904.407.7300.**

### ***Nausea/Vomiting***

Nausea, vomiting and dry heaves are usually temporary and can be successfully treated. Symptoms may be caused by illness, strong odors, treatments and some medications.

*What you can do:*

- Encourage the patient to eat slowly and chew food thoroughly.
- If nausea occurs only between meals, give frequent, small meals, snacks at bedtime and leave food within easy reach.
- Find food the patient likes. Many patients don't like the taste of red meat or meat broth. Serve other protein choices.
- Offer clear liquids served cold and have the patient sip them slowly. Fruit punch or non-carbonated drinks may be a good choice.
- Have the patient suck on mints or hard candy.
- After the patient eats, have him/her rest in a semi-reclining or sitting position.
- In the morning, serve dry foods like toast or crackers.
- Avoid serving fried, spicy and fatty foods.

- Avoid strong odors such as perfumes or aftershave.
- Provide good mouth care.

*If the patient is vomiting:*

- If bedridden, be sure the patient is placed on his/her side so the vomit will not be inhaled.
- Provide liquid in the form of ice chips or frozen juice chips.
- Give sips of ginger ale, peppermint tea or non-carbonated drinks.
- Keep a record of how often and how much the patient vomits.

*What **not** to do:*

- Do not force food or fluids on a patient who is nauseated or vomiting.
- Do not allow the patient to lie flat.

Your Community Hospice team can help with nausea and vomiting. Talk to your nurse or **call the 24/7 Patient Priority Line for help.**

## **Seizures**

People sometimes have seizures as a result of their illness or medications. A seizure is the uncontrolled movement of muscles, usually lasting fewer than five minutes. The seizure may be followed by loss of consciousness, periods of sleepiness and/or confusion.

*Signs to look for include:*

- Eyes rolling back or blank stare.
- Sudden loss of bladder or bowel control.
- Jerking movements, especially the arms and legs.

*Some suggestions to help a patient who is having a seizure:*

- Stay calm.
- Stay with the patient.
- If possible, prevent falling by easing the patient to the floor.

*During the seizure:*

- Turn the patient on his/her side.
- Don't restrain or try to stop any movements.

- Remove any hard or sharp objects from the area.



- Loosen any tight clothing, such as a collar or belt.
- Place something soft and flat under the patient's head (you can use a folded blanket or pillow).
- Never force anything into the patient's mouth.
- Ask unnecessary visitors to leave the area.
- Dim the lights.

*After the seizure:*

- Let the patient lie quietly.
- As the patient begins to wake up, gently call his/her name, and tell where he/she is and what has happened.
- Don't give food, liquid or medicine until the patient is completely awake.
- If this is a first-time seizure or the patient is hurt or bleeding, call the 24/7 Patient Priority Line immediately.
- Write down what you remember about the seizure, such as how long it lasted, what the patient was doing before the seizure and the type of movement that happened during the seizure so you can tell the Community Hospice nurse.

## **Sweating**

Heavy perspiration, especially at night, may happen with or without fever. Sweating can be caused by a fever, the body's reaction to a tumor, infection, breathing difficulty or hormone changes.

The following will help you keep a sweating patient dry and comfortable:

- Offer acetaminophen (e.g., Tylenol®) to reduce fever, if appropriate.
- Use layers of clothing with a cotton layer next to the body. Cotton absorbs moisture and pulls it away from the skin.
- Change wet clothing as soon as possible.
- Change bed linens if they become wet.
- Consider a daily bath, which can prevent skin irritation.

- Use a comfortable amount of blankets.
- Avoid letting the patient become chilled.
- Keep the room at a moderate temperature—not too hot or too cold.
- Try to keep the patient calm; anxiety can cause sweating.

**Call the 24/7 Patient Priority Line at 904.407.7300** if a fever above 101 degrees doesn't respond to acetaminophen (e.g., Tylenol®) or if chills continue.

### ***Urine Elimination***

Patients often have issues with urine elimination. Your Community Hospice nurse can help if the patient has issues with urine control or decreased urine elimination. Your nurse may discuss the need to place a catheter (tube) into the patient's bladder to drain the urine.

If your physician orders the catheter and everyone is in agreement, the nurse will place the catheter and teach the patient and caregiver how to take care of it. Briefs are also another option.

### ***Urinary Catheter Care/Irrigation***

A urinary catheter is a tube that runs from the bladder to a collection bag used to collect urine. Your nurse will insert the catheter and provide instructions regarding its use.

Some common problems with catheters that you will need to let your nurse know about or call the 24/7 Patient Priority Line include:

- Burning or pain
- Sudden decrease in urine through the catheter
- Leaking of urine around the catheter
- Blood or mucus around the catheter

*Things to remember about catheters:*

- Always wash hands before and after working with the drainage bag.
- Check the tubing to make sure it is not twisted, pulled too tight, kinked or under the patient.
- Make sure the collection bag is hanging below the level of the patient's body; never lift it above the body.
- The drainage bag should be emptied one or more times per day.



- Irrigate the catheter as directed by the physician and as the nurse has instructed.

#### *Cleaning the catheter*

- To clean the catheter, begin by washing the area around the catheter gently with mild soap and warm water, rinse and then pat dry.
- Clean the catheter area every day and after each bowel movement.

#### *Irrigating the catheter*

If a catheter becomes blocked, irrigating the catheter can restore the flow of urine. Catheter blockage should be suspected if the urine flow has stopped and there are no kinks in the lines, and the collection bag is below the level of the patient.

**Important:** Irrigate the catheter on your own **only** if you've been given a physician's order. **Call the 24/7 Patient Priority Line at 904.407.7300** if this is your first time irrigating the catheter or if you have any questions or concerns.

#### *To irrigate:*

- You will need the irrigation tray and syringe, sterile saline solution, alcohol wipes and waterproof bed pad provided by your nurse.
- Place a waterproof bed pad under the work area to protect the bed linens from any spilled urine.
- Wash your hands well and put on gloves.
- Pour sterile saline into the irrigating container (about  $\frac{1}{2}$  cup).
- Remove the cover tip of the syringe without touching since it is sterile. Keep the cap nearby.
- Separate the tubing from the bag.
- Remove the cap from the syringe and fill syringe  $\frac{1}{2}$  to  $\frac{2}{3}$  full with sterile saline from the container. Push the tip of the syringe into the catheter until it fits snugly.
- Gently push the solution into the catheter. If you meet a lot of resistance, stop and reconnect the tubing to the catheter and call the 24/7 Patient Priority Line.
- If the solution goes in easily, disconnect the syringe and let the catheter drain into the irrigation tray.
- Replace the cap on the syringe and discard.

- Reconnect the catheter to the drainage bag and tubing.
- Dispose of urine and any unused saline solution.
- Remove gloves and wash your hands.

**Call the 24/7 Patient Priority Line** if you experience any issues with the catheter or if you have any questions.

## FOOD AND WATER: A HOSPICE PERSPECTIVE

*She never feels like eating. I try to give her food so that she can keep up her strength. I can't let her starve. What can I do?*

Your Community Hospice team hears questions like this asked by almost every family member they work with. Often times ill patients experience a loss of appetite and subsequent weight loss as their illness progresses. The patient's family sees food not only as necessary for survival, but also as a source of caring, nurturing and comfort.

While the family members focus on the need for food and insist that the patient eat even when he/she says "no," the patient rarely becomes concerned about his/her own loss of appetite. This conflict can be emotionally painful to everyone and may lead to friction within the family. This adds more stress to the family system as the disease progresses.

For the hospice patient, nutrition is an issue that is discussed at almost every team visit. As with other aspects of hospice care, nutrition has physical, psychological and spiritual issues related to it. Your Community Hospice team members will work with you and your family to prepare for the changes that will occur as the disease progresses. The team will explain why the changes are happening, what options for care are available, what outcomes can be expected of each intervention, and to then support you in your decisions.

Concerns related to hydration and nutrition are emotionally charged. Patients and families need to understand that weight loss and loss of appetite are part of the disease progression and the dying process. While medical treatments are available to reduce many of the problems experienced by hospice patients, there is little to offer in reversing this weight loss. The human body has many ways of adapting

during the dying process. Reduced interest in food and water is one of nature's strategies that allows the patient to die more comfortably and peacefully.

In the early stages of the terminal illness, it is appropriate to offer the patient his or her favorite foods in small quantities throughout the day. During this time, the patient should be encouraged to eat and drink. It is helpful for families to know what amount of food they can expect for the patient to eat and drink.

Some practical suggestions for nutrition:

- Offer small, frequent meals.
- Softer foods are easier to swallow.
- Avoid foods with high acid or fat content.
- Cooler foods are more easily tolerated.
- Try to serve the foods that are being tolerated well.
- Provide mouth care as directed (see the *Mouth Care* topic in the *Caregiver Tips* section of this guide).

When the patient's level of activity decreases, the metabolic rate slows down and the amount of calories needed daily will decrease. As the disease progresses, encouraging the patient to eat and drink does not work. Forcing food and liquids may cause not only physical discomfort, but emotional discomfort as well. An increase in the amount of food ingested will not significantly increase the patient's life expectancy. Your Community Hospice nurse will assess the patient's appetite and treat symptoms such as mouth sores, nausea, vomiting, constipation and pain.

### ***Adding Calories***

So much of life revolves around eating and drinking—daily meals together, holidays, major events and even religious ceremonies. Eating is usually a pleasure, but during an illness, eating may take special effort. Not being able to eat, drink or share in meals as before can stir up deep emotions.

When you or your family member is ill, good nutrition cannot be measured by the amount of food you eat or the number of calories you take in. Even people who eat well may continue to lose weight.

Many changes may take place during an illness that can affect food intake. You or your loved one may experience the following: loss of appetite; food may not be interesting; nausea, vomiting, diarrhea or constipation; or sore mouth or throat with difficulty swallowing.

Any of these problems can make eating difficult or undesirable. Often these symptoms are temporary, so don't feel guilty if you are unable to eat. If you are the caregiver, don't force unwanted food.

Each person's experience is unique. Use these tips as a guide and try many different ways to see which works best:

- Encourage the patient to eat when and as much as he/she wants.
- Plan 5-6 mini-meals and snacks each day that consist of favorite foods.
- Encourage the patient to eat whatever foods sound good or look appetizing.
- Offer small portions.
- Consider using a blender or food processor to make foods easier to swallow.
- Serve easy-to-eat foods such as casseroles, macaroni and cheese, puddings, ice cream and hearty soups.
- Keep snacks or finger foods on hand and easy to get to. Some suggestions include yogurt, cereal and milk, cheese and crackers, egg salad, deviled eggs, gelatin, and peanut butter and jelly.
- Avoid strong cooking odors or unpleasant smells.
- Avoid fried, spicy and fatty foods that may be more difficult to digest.
- Improve the taste of some foods and add calories by adding fruit or liquid supplements.
- Serve colorful foods or favorite dishes.
- Place the food on an attractive plate or add a small vase of flowers when serving the meal.
- Have the patient eat in a favorite room or place.
- Serve a meal when the patient is free from pain, relaxed and rested.
- Offer several selections to choose from, as well as different amounts.
- Serve beer or wine, if allowed. It can improve the taste of food or increase the appetite.

## Recipes

The following items are usually appealing and easy to eat.

### *Banana Malt*

- 1 ripe banana frozen (peel and place in plastic bag overnight in freezer)
- $\frac{3}{4}$  cup fortified milk
- 3 tablespoons chocolate malted milk powder
- Put ingredients in a blender
- Blend until smooth

### *Banana Shake*

- 2 ripe bananas sliced
- 14 ounces condensed milk
- 1 cup cold water
- $\frac{1}{3}$  cup lemon juice concentrate
- Mix together or use blender (if blender is used, add 2 cups of ice cubes)

### *Chocolate Frosty Kick*

- $\frac{1}{3}$  cup chocolate-flavored drink mix such as Nesquik®
- 1 cup fortified milk
- $\frac{1}{4}$  teaspoon cinnamon
- 1 scoop vanilla ice cream
- Put ingredients in a blender
- Blend until everything is combined

### *Chocolate Peanut Butter Shake*

- $\frac{1}{3}$  cup chocolate-flavored drink mix
- 1 tablespoon peanut butter
- $\frac{1}{4}$  cup fortified milk
- 2 scoops vanilla ice cream
- Put ingredients in a blender
- Blend until everything is combined

### *Orange/Pineapple Shake*

- 1 pint orange sherbet
- 3 cups orange/pineapple juice
- Put ingredients in a blender
- Blend with crushed ice

#### *Pudding Shake*

- 1 box instant pudding (flavor of choice)
- Mix with milk as package directs
- Add 1½ cups of ice cream
- Put ingredients in a blender
- Blend to desired consistency
- Add milk to thin

#### *Quick Breakfast Drink*

- 1 ripe banana frozen (peel and place in plastic bag overnight in freezer)
- 1 tablespoon wheat germ
- ¾ cup fortified milk
- 2 teaspoons honey
- ¼ teaspoon cinnamon
- Put ingredients in a blender
- Blend until smooth

#### *Strawberry Flip*

- ¼ cup strawberry drink mix such as Nesquick®
- 1 tablespoon lemon juice
- ⅓ cup cold water
- Put ingredients into a large glass or cup
- Stir briskly
- You may add 2 scoops of lemon sherbet

#### *Strawberry Smash*

- ⅓ cup strawberry drink mix such as Nesquick®
- ¼ cup applesauce
- Vanilla ice cream
- Mix drink mix with applesauce
- Stir in ice cream
- Add carbonated water if desired

#### *Strawberry Soda*

- ⅓ cup strawberry-flavored drink mix such as Nesquick®
- ½ cup fortified milk
- 2 scoops vanilla ice cream
- Put ingredients in a blender
- Blend until everything is combined
- Add carbonated water if desired
- Top with whipped cream

## ***More Ways to Add Calories***

It is sometimes hard to eat enough food to give your body the calories needed to keep up energy levels. There are ways to boost the amount of calories you take in without having to eat more food.

Commercially made nutritional supplements are available at pharmacies and grocery stores. Ask your Community Hospice nurse about whether supplements are appropriate. Your nurse will consult with the Community Hospice dietician to determine what may be appropriate.

The following suggestions and recipes can help add calories (and energy):

### *Fortified Milk*

- 1 cup powdered milk to 1 quart whole milk
- Use fortified milk in shakes, puddings and sauces

### *Instant Breakfast*

- Variety of flavors available
- Add ice cream or whipped cream
- Use fortified milk

### *Instant Pudding*

- Add whipped cream
- Use as a thickener in milk drinks

### *Instant Potato Flakes*

- Add to cream soups for more calories and to thicken

### *Fruit Purees or Baby Food Fruits*

- Use applesauce to thicken fruit juices
- Add blended fruit to shakes or instant breakfast
- Freeze juices in ice cube tray to use in tea, lemonade and other drinks

### *Sweeteners*

- Add extra sugar to tea, juices or flavored gelatin
- Use sweetened condensed milk in hot drinks
- Use corn syrup or honey in food or drinks
- Use crushed candy bars in milkshakes to increase calories
- Add chocolate syrup

### *Thickened Liquids*

- Thickened liquids move down the throat slowly and help to avoid choking
- Instant pudding, instant potato flakes, applesauce, flavored or unflavored gelatin may be added to food/fluids
- Drink boiled custard
- Flavored gelatin at room temperature can be stirred gently and served as a thickened liquid

### *Protein Supplements*

- Yogurt made with whole milk
- Soy milk
- Protein powder
- Non-fat dry milk
- Instant breakfast drink mix



## CAREGIVER TIPS

Our goal is to provide assistance and advice to help make these days with your loved one easier and more enjoyable. Please review these tips when caring for someone with a serious illness at home.

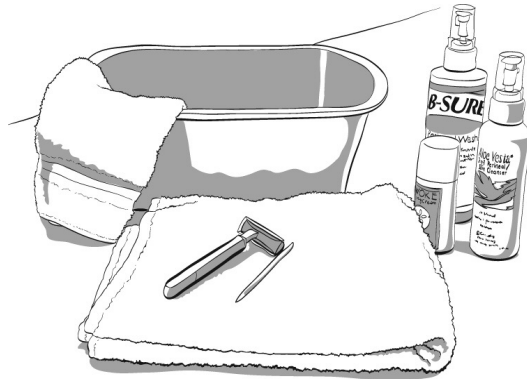
### **Bathing**

A bath or shower is always refreshing. However, there are times when a bath or shower is not safe or possible. In such circumstances, bed bathing may be a desirable alternative for the patient.

Community Hospice certified nursing assistants can help with bathing the patient. Please ask your Community Hospice nurse to arrange this.

You may choose to bathe the patient in bed on your own. If so, Community Hospice recommends the following steps to help guide you:

- Gather supplies, including mild soap, a soft wash cloth and towel, wash basin and lotion.
- Place all supplies near the patient.
- Be certain the water being used is warm, but not too hot.
- Change the water frequently, if necessary, to maintain freshness and a comfortable temperature.
- ***Uncover only one part of the body at a time so the patient is warm and comfortable.***
- Begin with the face, and work from head to feet, including the back.
- Soap an area of skin, rinse well and pat dry.
- Discard water after cleaning the feet.
- Using fresh water, wash genitals and buttocks, working from front to back and drying thoroughly.
- Make sure all skin folds and crevices are dry to prevent chapping.
- Discard water after cleaning genitals and buttocks.
- Apply lotion to any red areas and massage gently. Use lotion on the patient's back and consider giving a back rub.



## Mouth Care

Cleaning the mouth provides several benefits for the patient—helping to prevent sores or infection, and possibly improving the patient's appetite. Mouth care needs to be done even if the patient is not eating or drinking. Cleanse the mouth two or three times a day using a mouth swab or a soft toothbrush.



Cleansing can also help with the uncomfortable condition of dry mouth. If the patient is able, allow him/her to do his/her own mouth care. If you have any questions, talk to your nurse.

How to provide mouth care:

- Raise the head of the bed and place a clean cloth under the patient's chin.
- Remove any dentures and place them in a container of water.
- Have patient sip water to moisten the mouth.
- Apply toothpaste to the brush or swab and gently brush teeth, gums and tongue.
- Allow the patient to alternate between sipping water and spitting.
- Finish with cool water and/or mouthwash as desired.
- If dentures were removed, brush them with toothpaste and rinse before replacing them into the clean mouth.
- Pat lips dry with a clean cloth and apply lip balm to prevent dryness; reapply often.

If the patient is unconscious, unable to swallow or to sit up, do not give mouth care as outlined above. Your Community Hospice nurse will provide special instructions.

## Skin Care

Basic skin care is important, especially when someone is ill. Regular hygiene, such as bathing or taking showers, and applying lotions to dry skin should continue.

Patients sitting for long periods or staying in bed most of the time require special skin care. Skin breakdown and pressure sores often occur when there is a prolonged period of bed rest or nutrition is poor. Buttocks, shoulders, heels, elbows, hips and other bony parts are particularly at risk for developing pressure ulcers.

Guidelines to minimize skin pressure problems:

- Check skin for reddened areas.
- Look especially at heels, elbows, buttocks, hips and shoulders.
- Keep skin clean and dry—especially skin-to-skin contact areas (between legs, under breasts, in fold of abdomen).
- Change pads soiled with urine or stool as soon as possible.
- Gently wash genital area with mild soap; rinse with warm water.
- Keep dry, flaky skin lubricated with lotion.
- Keep heels off the bed by placing a pillow under the patient's calves.
- Turn and position the body using these guidelines:
  - Turn or change position every two hours as tolerated.
  - Prop up the patient with soft pillows.
  - If sitting, shift weight frequently.

Remember to show your Community Hospice nurse any problem areas or changes to skin to help prevent as many issues as possible.

## MOVING THE PATIENT (TRANSFER)

When assisting a patient with movement, try using devices such as a lift sheet or trapeze bar to allow the patient to do as much as possible and ensure patient safety. Ask your Community Hospice nurse for more information about these devices.

Before starting, remember to take care of your own back. Bend your knees, keep your back straight and reach as little as possible.

If the patient has had a stroke, transfer him/her from the strong, unaffected side of the body.

Whenever you move the patient, explain what you are going to do before you begin. Also, try to tell the patient what you are doing while you are doing it. This will help him/her understand what is happening so he/she can help you, if possible, and will also help reduce fear and anxiety.

### ***Assisting the Patient From Sitting to the Standing Position***

- Assist patient in moving to the edge of the bed or chair.
- Make sure the patient's feet are flat on the floor.
- Stand directly in front of the sitting patient with your feet shoulder-width apart.
- Tell the patient to place his/her hands on your shoulders.
- Place your hands under the patient's arms. Brace yourself by bending your knees and keeping your back straight.
- Straighten yourself, gently raising the patient. Allow the patient to pull on your shoulders.
- Do not let go unless you are sure the patient is stable.



### ***Helping the Patient Move From the Bed to a Chair, Wheelchair or Bedside Commode***

- Explain to the patient what you are planning to do.
- Move slowly.
- Put the head of the bed up and have the patient turn toward the edge of the bed.
- Swing the legs down to the floor as you bring the patient to a sitting position. Wait a few moments to allow the patient to adjust to sitting up.
- Make sure the patient's feet are flat on the floor.
- Place the chair, wheelchair or commode next to the bed so it is facing the head or foot board, keeping it as close to the bed as possible.

**Note:** When transferring to or from a wheelchair, lock the brakes and move the leg rests out of the way.

- Face the patient and straddle his/her feet with your feet.
- Follow the steps for assisting the patient from sitting to the standing position.
- Once the patient is standing, pivot him/her toward the chair; use your feet to guide the patient's feet as you turn.
- Lower the patient to the chair, bend your knees and keep your back straight.
- Reverse steps to return the patient to bed.



### ***Assisting the Patient With Walking***

- Before walking with the patient, let him/her stand for a few seconds to get balanced.
- Support the patient by placing one arm around his/her waist or holding the clothes at the waist.
- Walk to the side of the patient.
- If patient is using oxygen, tubing should be held to the side away from the feet.
- Allow the patient to set the pace and stop for rest as needed.

### ***Using a Walker or Cane***

Some patients may require a cane or walker to assist with safe mobility. Your Community Hospice team will instruct you on how to adjust and use your walker or cane safely. (Refer to DME Troubleshooting Guide in the *Equipment Tips* section of this guide.) Make sure the patient does not use a walker or cane alone until shown how to properly use the equipment. If the patient feels unsteady, the walker or cane should not be used unless someone else is home.

### ***Using a Shower Chair or Bath Bench***

A shower chair or bath bench can be used for patients who are walking with assistance and would prefer to shower privately. These devices are made of plastic and metal and usually fit in a standard tub or shower.

Helpful hints when using shower chairs and bath benches:

- Never allow the patient to use the shower chair or bath bench while home alone.
- Remove all throw rugs from the bathroom for safety.
- Clean the bench or chair with bathroom cleaner, making sure all soap is rinsed off to prevent slippery surfaces.

## ***Placing a Lift Sheet***

A lift sheet (also called a draw sheet) is a folded flat sheet used to move patients who can no longer move on their own. When used, it will help you position the patient without directly pulling on his/her body or creating too much friction, which can damage the skin.

To make and position a lift sheet:

- Tell the patient what you are going to do, before starting the process.
- Place a lengthwise folded sheet on the bed next to the patient along the back, from the shoulders to the thighs. Tuck at least half of the sheet under the patient, with the patient lying on his/her side facing away from you.
- Put the side rail up on the side you have been working on; move to the other side and put this side rail down, then assist the patient to roll over the folds of the lift sheet.
- Straighten out the sheet, smoothing out the wrinkles.
- Lift and move the patient as desired.



## ***Uses for a Lift Sheet***

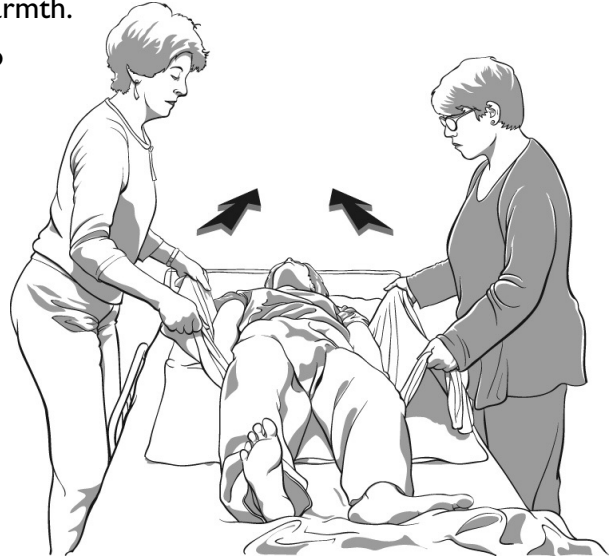
*When turning a patient from side to side in bed, you should:*

- Begin by telling the patient what you are going to do. This will decrease fear and anxiety.
- Raise the side rail on the side the patient is initially going to be turned toward, if the patient is in a hospital bed.
- Position the lift sheet as instructed previously.
- Move the patient closer to you as you stand at the side of the bed, using the lift sheet.
- Move the pillow toward the raised side rail, provide support for the head.
- Bend the knee that is on top.
- Turn the patient toward the side rail, with your hand on the closest shoulder and hip.

- Firmly place a pillow behind the patient's back for support.
- Place other small pillows or folded towels between his/her knees and ankles.
- Adjust the shoulders, pulling the bottom shoulder slightly out. Add a pillow under the arm.
- Adjust head pillow for comfort. Ask if the patient feels comfortable. Put up both side rails and cover the patient for warmth.
- At times, it is not unusual for the patient to moan during the turning process.

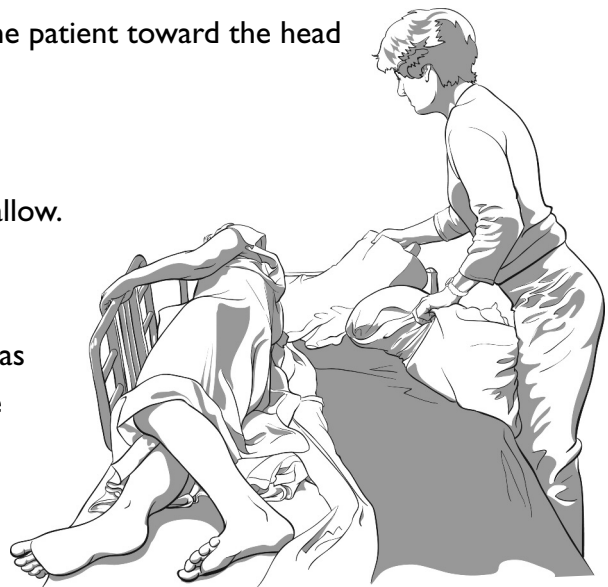
*Moving a patient toward the head of the bed:*

- Try to do this with another person, one of you on each side.
- Position the lift sheet as instructed previously.
- Lower the head of the bed as much as the patient will allow.
- Each person should grab the edge of the sheet around the shoulder and the edge of the sheet by the hips.
- On the count of three, lift and move the patient toward the head of the bed.



**Changing Sheets With a Patient in the Bed**

- Position bed as flat as the patient will allow.
- Keep the side rail up, the one opposite from the caregiver.
- Turn the patient to the side and move as close to the rail as comfortable for the patient. Use a lift sheet if necessary.
- Bed pads are another item that may be placed under the patient while on his/her side.
- Pad the rail with an extra blanket(s).
- Working from one side, loosen the bottom sheet and tuck as much as possible under the patient.



- Attach the top and bottom corners of the clean sheet on the side you are working.
- Smooth the clean sheet over the patient, then fold and tuck the sheet under him/her. It is best if you tuck the clean sheet under the dirty sheet.
- Put up the side rail, then move to the other side of the bed and lower this rail.
- Help the patient roll over the lump of dirty and clean sheets.
- Pull out the dirty sheet(s).
- Pull the clean sheet tight and attach to corners.

### ***Placing a Patient on a Bedpan***

- Put on gloves.
- Powder the bedpan to avoid any injury to the skin.
- With the opposite side bed rail up, roll the patient to that side.
- Place the bedpan squarely on the buttocks.
- Roll the patient back over the top of the pan.
- Check between legs to make sure the patient is properly seated on the bedpan.
- Raise the head of the bed.
- Put up the other side rails.
- Always be sure to check on the comfort of the patient and make sure the bed rails are in the up position.
- Stay within calling range or leave a bell nearby.
- When the patient is done, roll him/her off the bedpan. Be careful not to let the pan tip.
- Help clean the patient and pat dry.
- Dispose of waste in the toilet, clean out bedpan.





# INFECTION CONTROL

**REMEMBER: The most important infection control measure is to wash your hands.**

Caregivers should wash their hands frequently, both before and after providing care, preparing food or eating. Do not forget the patient's hands. Hand sanitizers are also a good choice.

## ***How to Properly Wash Your Hands***

- Remove any jewelry.
- Use the warmest water you find comfortable.
- Apply liquid soap and lather.
- Count to 20 as you wash, making sure to clean between your fingers. Don't forget to wash under your nails and around your cuticles, and use a fingernail brush when possible.
- Rinse well using warm water and dry completely. If the sink area is used by multiple people, use paper towels instead of a cloth towel.

In addition to washing your hands regularly, it is important to follow certain guidelines to prevent infections. Some basic rules and guidelines are below. Please discuss any questions or concerns with your primary nurse.

### *Use gloves*

Disposable gloves need to be used when the caregiver may be in contact with blood, bowel movements, urine or other bodily fluids. As soon as a task is done, throw the gloves away and wash hands well.

### *Clean up patient area*

Trash that has blood or other body fluids should be placed in a plastic, leak-proof bag for regular trash disposal. Clean spills of body fluids immediately with 10 percent bleach and water solution. **Note:** Do not use a bleach solution on carpet. If the clean-up is done by hand, wear disposable gloves. Soiled sponges and mops can be disinfected by soaking in a 1:10 dilution of bleach for five minutes.

### *Needles, syringes and other sharp objects*

If the patient uses these items, dispose of them in a sharps container provided by Community Hospice. When the container is three-quarters full, seal the container, and notify your primary nurse who will remove the container and replace it with a new one. Please keep out of reach of children.

### *Laundry*

Proper handling of laundry is also an important measure of infection control. Wear gloves to handle clothing and bed linens soiled with blood or body fluids. Wash soiled clothing and linens as promptly as possible. If body fluid stains are present, put linens through the cold wash cycle first. Then wash in hot water with one cup of bleach added to the wash cycle.

### *Infectious waste disposal*

Appropriate waste disposal is necessary to prevent transmission of infectious agents. Flushable waste should be flushed down the toilet. Non-flushable materials containing body fluids (e.g., wound dressings, diapers, paper towels) should be placed in a plastic bag and securely closed, then placed inside a trash bag that is also securely closed.

## SAFETY IN THE HOME

Please report to your Community Hospice team any unsafe conditions that you are aware of in your home and help maintain a safer environment by removing or correcting any hazards.

### **Fire Safety**

*Takes these steps to prevent a fire:*

- Do not use extension cords.
- Do not use appliances or equipment with frayed cords.
- Do not use electrical equipment near water.
- Remove clutter.
- Keep all exits clear.
- Keep portable heaters 3–4 feet away from objects.
- Never use the burners on a gas or electric kitchen stove to heat the house.
- Install smoke detectors. In the event of a fire, a smoke alarm can save your life and those of your loved ones. They are the most important means of preventing fire fatalities.

- Smoke alarms are easy to maintain. There are two steps to remember:
  - Replace the batteries at least once a year.
  - Keep them clean. Dust and debris can interfere with their operation, so clean your smoke alarms regularly.

*If you use oxygen tanks in the home:*

- Never use this equipment until you have received instructions on proper usage and maintenance.
- Do not use petroleum-based products like Vaseline®; use only water-based products like K-Y® jelly.
- Post signs that oxygen is in use.
- Never allow smoking in the home.
- Do not light a flame such as a candle or ignite gas appliances while oxygen is in use.
- Oxygen tanks should be stored upright and never in an enclosed place such as a closet.

### **Falls Prevention**

Anyone can fall, no matter how strong or sure-footed. Many factors can lead to a fall, such as tripping over a rug, slipping on a slick surface or misjudging a step. Certain things can make falls more likely to occur for a seriously ill person, including:

- Weakness due to illness
- Problems with balance
- Poor vision
- Certain medicines or a combination of medications may cause drowsiness
- Hazards like rugs on slippery floors and clutter in the walkway

*As a caregiver, you can help prevent an accident by taking the following steps:*

- Have the patient sit upright and count to 10 before standing to minimize imbalance.
- Make sure the patient uses a cane or walker, if prescribed, and help if he/she is unsteady.
- Provide good lighting; use night lights or keep lights on at night.
- Remind the patient to move slowly, trying not to hurry, especially with turns.
- Have the patient wear slippers with “tread” on the soles.
- Make sure shoes are supportive.

- Be aware when the patient is going up or down stairs.
- Keep walkways and halls free of clutter.
- Keep area carpets in place with rubber mats.
- Do not use rugs in the bathroom or kitchen.
- Avoid using wax on floors.
- Clean up spills immediately, and do not walk on the floor until completely dry.
- Fix uneven flooring.
- Replace any loose floor tiles.

*Tips for preventing falls on stairs:*

- Secure handrails on at least one side of the stairs.
- Install non-skid treads on the stairs.
- Keep adequate lighting on the stairs.

*Use the following items to make the bathroom safer:*

- Toilet extension seat
- Grab bars
- Shower chair
- Nonskid mats
- Liquid soap
- Hand-held shower head
- Dry floors
- Night lights

*Other home safety tips:*

- Leave the bathroom door unlocked in the event the patient needs help.
- Keep all bath items within reach.
- Put a large towel on a closed toilet or chair to provide a place to sit down and dry off.
- Give the patient a bath or shower when he/she is not too weak, or have someone else available to help.

## EMERGENCY PREPAREDNESS

Your safety is our concern. Planning ahead can help you remain calm in an emergency.

All Community Hospice patients and their families are encouraged to develop and practice an emergency plan for potential disasters. Your psychosocial specialist will assist you in developing a patient emergency preparedness plan.

Patients and families who live in an evacuation zone or in a mobile home must have an evacuation plan. Evacuation choices may include:

- A friend's or relative's home in a safe area
- A motel in a safe area
- A designated special needs shelter. These public shelters are equipped to shelter you if you are oxygen-dependent, but they may allow only one other adult to stay with you. Other family members should make arrangements for children, other family members and pets.

**Note:** We recommend that **a special needs shelter should always be your last resort.**

If you are using a shelter in the event of a disaster, our psychosocial staff can provide you with your county's special needs evacuation registration form to be completed as you prepare your evacuation plan.

You will also need to decide on your method of transportation during an emergency. Options include:

- Driving the family car
- Having friends or relatives assist you with evacuation transportation
- Registering with the county to be transported (requires a "special needs evacuation registration"; please ask your psychosocial specialist to assist you).

Familiarize yourself with evacuation routes from your location to your destination. If your plans for evacuation change—for example, you decide to shelter in place or stay in a different location call the **24/7 Patient Priority Line at 904.407.7300** to update your information.

*Remember:*

- If you have pets, have a pet plan in place. All shelters are not pet-friendly. Do not leave pets at home unattended.
- When you return to your home after the disaster is over, please call the **24/7 Patient Priority Line at 904.407.7300** to notify us regarding your condition and location.
- In the event of a natural disaster, Community Hospice staff will not be able to visit you until the disaster is declared over and it is safe to travel.

**Evacuation Checklist**

Below is a list of items to prepare before evacuation, especially if you are receiving evacuation transportation assistance. You and your caregiver must be ready when your evacuation transportation vehicle arrives, even if the weather is clear.

*Medications and Important Papers:*

- All prescription and non-prescription medications to last 10 days
- Medical equipment and all necessary supplies
- If oxygen-dependent, bring all equipment instructed by the county emergency management contact
- Name and telephone number of your physician
- Community Hospice **24/7 Patient Priority Line number—904.407.7300**
- Advance directives, including executed, yellow Do Not Resuscitate (DNR) form, if applicable
- Personal phone book and a list of important numbers
- Identification with current address and any other important papers, in a water-proof bag

*Personal Items, Clothing and Bedding:*

- Enough clean clothes and personal hygiene items for three to five days
- Glasses, hearing aids and batteries, prosthetics and other assistive devices such as walker or wheelchair
- Bed sheets, blankets, pillow, folding lawn chair, air mattress or cot
- Personal items such as toiletries and dentures

*Miscellaneous Items to Consider:*

- Special dietary items and food for 3–5 days
- One gallon of water per person per day (plan 3–5 days)
- Books, magazines and quiet games
- House and car keys
- Flashlight and batteries
- Cell phone and charger

*Other Tasks to Consider:*

- If possible, turn off electricity, water and gas before you evacuate.
- Make plans for your pets.
- Notify family/friends, including those out of state, of your plans and site for evacuation.

***Loss of Telephone/Communications***

If there is a loss of communications in your area, we will work to re-establish contact with you as quickly as possible.

If you have a cell phone, keep the battery charged. Also, consider that land-line, hard-wired phones may perform best during a weather emergency. As part of your disaster plan, provide an out-of-state contact phone number to your Community Hospice team, and let this contact know when and where you are sheltering.

If necessary, during a crisis or in an emergency, call 911 from the nearest working telephone or go to the nearest hospital emergency room. Notify your Community Hospice care team of this as soon as possible.

***Loss of Power***

Notify your Community Hospice care team of this as soon as possible so we may assist you with equipment needs as appropriate. If you are on oxygen, use the backup oxygen tanks until power is restored.

***Disaster Planning Resources***

An excellent local resource for developing a disaster plan can be found at: [FloridaDisaster.org](http://FloridaDisaster.org) and click on the “Get a Plan” link.





## PATIENT PRIORITY LINE

***Call the 24/7 Patient Priority Line anytime—  
904.407.7300, 877.699.7300 (toll free)***

We are always available to assist you—24 hours a day, 7 days a week, 365 days a year.

Questions, concerns or problems often can occur during the night or on weekends. Be assured that Community Hospice nursing and/or medical staff is always available through our **24/7 Patient Priority Line** at **904.407.7300**. The staff will help you over the phone or come to your home if needed. Please do not hesitate or wait to call with a question or concern.

When you call, please have your patient security code number ready so the nurse on the phone can easily access your information and plan of care. Your patient number is located on the first page of this guide.

If you call and reach voice mail, please state your patient number, your name and the reason for your call. We will promptly call you back. Do not use your phone while waiting for the return call, and if you haven't heard from us within 15 minutes, please call back.

## RECOGNIZING AND MANAGING PAIN

There may be times during the illness when pain is present. This pain may be related to the disease, anxiety or fear. Only the patient knows how it feels and can adequately describe the pain. Whatever the cause may be for the pain, there is no need to suffer.

When pain is present, your loved one's life can be affected in many ways. You may notice the following symptoms: loss of appetite, inability to sleep, restlessness, anger, withdrawal, exhaustion. There also may be other reasons for these behaviors, as well as other causes for the discomfort that may not be related to the illness, such as arthritis or headache pain.

Ask your loved one if he or she has pain. Remember pain is whatever the patient says it is, occurring whenever and wherever the patient says it does. Your team at Community Hospice is concerned about comfort, so keep us informed of the patient's level of pain and if it is not being controlled. You may find it helpful to record the patient's pain level on the *Pain Control Diary* found in the *Forms and Resources* section of this guide.

People have different coping patterns and may not always look like you think a patient with pain should look. Patients may display any of the following, either at rest or while being moved:

- Sleeping a lot or having difficulty sleeping
- Using terms such as “hurting,” “aching” or “hurts all over”
- Facial expressions such as grimacing, frowning, looking sad and wrinkling of the brow, especially in patients who are less alert
- Movements such as restlessness, fidgeting, moving slowly, protecting a body part, pacing, or rocking back and forth
- Verbal expressions such as moaning, groaning or crying out
- Difficulty concentrating
- Rubbing or protecting the place that hurts
- Changes in eating patterns
- Changes in usual behaviors (e.g., a vocal patient becomes quiet or a quiet patient becomes vocal)
- Changes in activity levels, or resisting activity or movement
- Withdrawal from friends and family

## PAIN MANAGEMENT ASSESSMENT

**ASK** about ability and willingness to use a pain rating scale. Which scale is most appropriate?

**BELIEVE** whatever is reported by the patient and document. Whenever there is a patient and caregiver discrepancy, final decision regarding treatment will be according to the patient report.

### **Responsive Patient—Use Numeric Pain Rating Scale** (THIS MAY ONLY BE ANSWERED BY THE PATIENT)

- On a scale of 0 to 10, with 10 being the worst pain you can imagine, what is your current level of pain?
- What is the best your pain gets?
- Using the same 0 to 10 scale, what is an acceptable level of pain for you?

### **Post-Intervention: Patient Verbal Response** (THIS MAY ONLY BE ANSWERED BY THE PATIENT)

- You previously reported your pain level as \_\_\_\_\_.
- I'm following up to see how successful we were in treating your pain.
- On a scale of 0 to 10, with 10 being the worst pain you can imagine, what is your current level of pain?

#### **Numeric Pain Rating Scale:**

No pain			Moderate			Severe		Worst Imaginable		
0	1	2	3	4	5	6	7	8	9	10

### **Impaired or Non-Responsive Patient—Use FRAAC**

Provide a copy of the FRAAC assessment tool and discuss pain indicators with the caregiver at **each** review. Caregivers may only provide their observations, not a pain level number.

#### **Direct Staff Observation**

- What behaviors did you observe?
- Based on the observations the pain level is \_\_\_\_\_.
- What is the best the pain gets?
- What do you think is an acceptable level of pain for the patient?

### FRAAC Pain Rating Scale:

Categories	Score-0	Score-1	Score-2
<b>Face</b>	Unwrinkled brow  Unclenched jaw  Blank or content expression	Distressed appearance  Troubled, worried expression; wrinkled brow  Corners of mouth turned down	Alarmed or fearful expression  Open eyes / pleading expression  Clenched jaw  Scowling, stern face
<b>Respiration or breathing</b>	Normal/unlabored  Quiet breathing	Breathing is noisy  Difficulty breathing  Looks more strained  Increased breathing rate	Appears difficult for patient to breathe  Episodic bursts of rapid breaths  Gasping  Very loud, strained breathing
<b>Activity, movement</b>	Lying quietly  Open position  Moves easily, flaccid  No tense muscles  Appears restful	Squirming, uneasy, fidgeting  Clenched fists  Not content  Slightly restless	Arched or rigid; jerking  Forceful touching  Tugging or rubbing body parts  Appearance of trying to get away from pain  Legs drawn up/arms flailing; writhing
<b>Audible noise</b>	No sound/quiet	Moans, whimpers  Expressed pain  Hushed, low sounds  Crying	Loud, guttural moaning  Unpleasant-sounding noise  Screaming, yelling
<b>Consolability, ability to be comforted</b>	Content	Reassured by the sound of a loved one, soft touching, or caressing  Distractable	Inconsolable  Unable to comfort through distraction

### ***Post-Intervention: Cognitively Impaired/Non-Responsive***

- The previous pain level was at level \_\_\_\_\_.
- I'm following up to see how successful we were in treating the pain.
- Based on the observations, the pain is now a level \_\_\_\_\_.

### ***Treatment of Pain***

For mild to moderate pain, over-the-counter medications or prescription medicine can be ordered.

For moderate to severe pain, your Community Hospice nurse will discuss a treatment plan with your team physician. Most pain medications are taken by mouth. If you or your family member has difficulty swallowing and cannot take a tablet or liquid, your physician may order other options, including:

- Suppositories
- Concentrated liquids under the tongue
- Patch on the skin
- IV pump

Some medications are long-acting, which means they are taken on a regular schedule (e.g., once a day) and work around the clock. There may be times when your pain returns before it is time to take your next dose; your physician may prescribe a short-term ("break-through") pain medication for these situations.

All medications have side effects, and pain medications are no different. Some medications can cause:

- Constipation
- Nausea and vomiting
- Drowsiness
- Dry mouth

Discuss any concerns or questions you have regarding pain and your medications with your nurse or **call the 24/7 Patient Priority Line at 904.407.7300 with questions.**

### ***Taking Your Pain Medications***

Many people are concerned about taking pain medications and may think it is better not to take them as directed by your physician and nurse. The goal of pain treatment is to prevent your pain from getting out of control. Please consider the following:

- Take your medicine regularly, as ordered. Taking medicine regularly will keep pain under control. Never wait for the pain to get worse before taking your medication.
- If your pain gets worse at certain times of the day or during an activity, you may need to take an extra dose prior to doing that activity. Discuss with your nurse before taking any medications.
- Remember that once you feel pain, it is harder to get it under control.
- Keep a record of medications you have taken, especially if your pain is not well controlled, so your nurse can discuss it with your physician and make changes.

### ***Non-Drug Treatment of Pain***

Several techniques may be effective to control pain without medications, including:

- Breathing and relaxation
- Massage, pressure, vibration
- Applying hot/cold packs
- Aromatherapy
- Music
- Imagery
- Distraction
- Rest

For additional information about these methods, please speak with a member of your Community Hospice team. Our specially trained nurses, ARNPs and physicians will work with you to achieve pain relief.

## **MEDICATIONS**

Medication for treatment of symptoms related to your hospice diagnosis and plan of care will be provided by Community Hospice at no charge. Community Hospice provides medications to long-term care patients using the facility-contracted pharmacy.

Our physicians, ARNPs, pharmacists and nurses are experts in pain and symptom management. Your primary nurse will consult with your team physician and the Community Hospice pharmacist to determine the best medicines for comfort while honoring your wishes.

In an effort to make you more comfortable or minimize interactions with other medications, we may make therapeutic substitutions (similar drugs that work the same way) and generic medications to manage your symptoms.

Your Community Hospice nurse will offer instructions on the safe administration of medications and will review them with you at each visit and when changes occur. Your nurse and the Community Hospice pharmacist are here for you and available to answer any questions you may have.

### ***Receiving Your Medications***

Routine medication orders placed by the team to our in-house pharmacy Monday through Friday are delivered by 4 p.m. the following day. We will make certain that immediate-need medications are delivered as soon as possible. To meet regulatory requirements for maintaining control and accountability of medications, you or your authorized designee will be required to receive and sign for medication deliveries.

If you have any questions regarding medications, **call the 24/7 Patient Priority Line—904.407.7300.**

### ***Taking Your Medications Safely***

Your physician orders your medications to help treat your condition. It is important to take them safely:

- Read the labels and information that come with your prescriptions and take them as directed.
- Always check the label on the bottle to be sure you are taking the right medicine.
- Keep your medicine in the original bottle, safely away from children and pets.
- Medicines that look alike should be stored apart to prevent mistakes and confusion.
- Keep your medicine in a cool, dry place. Refrigerate medicine if requested.



- Keep track of the number of pills you have; your nurse will review and count your narcotics weekly or as needed.
- Keep medications in set locations so it is easier for you to remember to take them.
- Keep each family member's medications in separate locations.
- Keep tubes of ointments and creams away from toothpaste.
- Do not chew, crush or break any capsules or tablets unless instructed.
- Discard all medications that are no longer used or are expired.
- Call the 24/7 Patient Priority Line if your medications are running low.
- Do not share your medicines with family members or friends.
- Don't take over-the-counter (non-prescription) medications without checking with your Community Hospice nurse.
- Keep track of your medications with the medication list provided by your Community Hospice team.

### ***Comfort Care Kit***

After admission to our program, Community Hospice may issue you a "comfort care kit" containing emergency medications that you can use in a time of crisis. This sealed package contains a small quantity of several medications historically needed on an urgent basis for many patients when symptoms such as constipation, pain, anxiety, nausea or vomiting occur.

When you contact the 24/7 Patient Priority Line, a nurse will listen to your situation, and upon an order from your physician, may instruct you to open and use a medication from your comfort care kit. The kit should remain sealed until you are instructed to open it. We also ask you to keep it in a safe place, such as the refrigerator.

### ***Morphine Liquid Concentrate***

Pain is a common symptom for hospice patients, and Community Hospice physicians often prescribe morphine to control pain. Morphine and morphine-like drugs are commonly used to treat severe pain, and there is no evidence to indicate their use will make the patient die sooner or become addicted. If you have questions or concerns, your Community Hospice nurse can give you the information you need.

Morphine liquid concentrate works quicker than pills and is usually given when pills may not be the best way for you to take medications. Roxanol or morphine sulfate concentrate are forms of liquid morphine that work quickly and are absorbed through the mouth.

These medications don't need to be swallowed to work, yet they provide the same pain control as other forms of morphine. If swallowing is a problem, place the medication under the tongue, between the lip and gum, or in the cheek area.

### ***Rectal Medications***

If instructed by your nurse to give medications rectally, follow these steps:

- Collect the medicine, gloves and some water-soluble gel (K-Y® jelly). **Note:** Do not use petroleum jelly because it will prevent medication absorption.
- Wash your hands and put on gloves.
- If medicine is a suppository, remove the foil wrapper.
- If medicine is a pill or capsule, it can be inserted directly into the rectum. In some cases the medicine may be put into a gelatin capsule and then placed in the rectum.
- Put a large daub of gel on the suppository, capsule or pill.
- If possible, position the patient on the left side with his/her knees pulled to the chest.
- Instruct the patient to take a few deep breaths and relax as you gently insert the medicine into the rectal opening with a gloved finger.
- Push the medicine in as far as the length of your finger. If the rectum is full of stool, the medicine will not be in far enough to be effective. **Call the 24/7 Patient Priority Line for assistance.**
- There may be the need or a sensation to have a bowel movement after the medicine is inserted, but try to keep the medicine inserted for at least 20 minutes.
- Take off and discard the gloves, and wash hands.

### ***Community Hospice Policies for Medication Management and Destruction***

As required by the Conditions of Participation issued by the Centers for Medicare & Medicaid Services for Medicare-certified hospice programs, we are including the following policies about medication management and medication disposal.

#### ***Policy—Medication Management for Patients Residing at Home***

Community Hospice health care professionals, in accordance with their scope of

practice and laws and regulations, provide education and oversight in the management of medications ordered for patients' use at home.

*Purpose:*

To establish and maintain a safe and effective medication management program for adult patients residing at home.

To comply with all applicable federal, state and local health and safety laws, regulations and codes.

*Definitions:*

Comfort Kit—a kit containing medications which may be required for a patient's urgent symptom management needs. Medications may be administered from the comfort kit only after an order is obtained by the nurse.

First Dose—the initial dose of a medication the patient has not previously used.

Home Medication Administration Record—an accurate list of all medications ordered for the patient's use. This record is maintained in the patient's home to help promote safe administration of medications.

*Procedures:*

1. A list of allergies and medications that the patient is currently taking is obtained at time of admission to the hospice program and is reviewed and compared with medications being ordered. Any discrepancies are discussed with the patient's physician.
2. The nurse may develop and update information on a Community Hospice "Home Medication Administration Record," or an equivalent record as provided by the patient/caregiver that the patient/caregiver may use to assist them in knowing which medications to take and when to take them.
3. The medication administration record is routinely reviewed with the patient/caregiver and compared to the list of ordered medications in the hospice electronic medical record (EMR). The nurse revises the medication administration record when necessary and reviews the changes with the patient/caregiver.

4. If provided, the comfort kit for urgent symptom management needs may be used only after a physician has directed that a medication be given to the patient.
5. The interdisciplinary group (the Community Hospice team) determines the ability and willingness of the patient/caregiver to accurately and safely use/administer medications. Instruction to the patient/caregiver may include, but not be limited to:
  - an understanding of the appropriate use and purpose of all medications included in the plan of care
  - how and when to administer medications included in the plan of care
  - documentation of use/administration of medications
  - potential side effects/interactions of medications included in the plan of care and the importance of reporting any unusual effects
  - emergency response to adverse reactions
  - safe storage of medications
  - proper disposal of used medication patches or syringes, and medication no longer ordered for use
  - an understanding of when to call Community Hospice if difficulties or questions arise regarding the use/administration of medications
6. The nurse may also provide the patient/caregiver with instructions for filling a pill box with regularly scheduled medications up to the next nursing visit. The nurse may assist with filling a pill box and documents this need in the patient's plan of care. The nurse does **not** put any as-needed medications in the pill box.
7. During routine visits, the nurse counts any controlled substances and reviews routine and as-needed medications to determine supply needs and records same in the EMR. The nurse orders medications from the pharmacy according to the patient's supply needs.
8. Ongoing patient/caregiver teaching of safe and accurate medication use/administration and response to teaching is documented in the patient's clinical record. Identified needs are entered into the patient's plan of care.

Reference: Medicare Regulations Hospice Conditions of Participation (CoPs), March 2, 2016, 42CRF 418.106(a)(1), (c)(1), (d)(1), (e)(2)(i)

***Policy—Destruction of Patient Medications in the Home***

Community Hospice offers to help patients and caregivers dispose of medications supplied by Community Hospice and no longer utilized by a patient in the homecare setting, in accordance with applicable state and federal regulations.

Controlled substances in the patient's home are handled according to requirements of the Controlled Substances Act of 1970.

If the patient is in a long-term care or assisted living facility, the medications are destroyed according to facility policy.

Controlled medications in the home must be disposed of appropriately when they are no longer needed by the patient or at the time of death.

***Procedures:***

- I. Medications are disposed of using an Easy Drug Disposal kit (a tall white plastic canister, called the EDD kit). When medication is placed in the EDD kit and water is added, the medications begin to dissolve. The following may be placed in the EDD kit:
  - Tablets, capsules, etc.
  - Liquids (2 ounces or less)
  - Patches—remove from package and place in canister
  - Suppositories without the wrapping
  - Controlled creams—squeeze into canister

Items are covered with water or liquid medication and the canister is shaken.

*Exceptions:* Large-volume IV solutions and large-volume liquid medications (non-controlled) may be disposed of by pouring down the drain. Creams and ointments (non-controlled) may be disposed of in the waste bag.

2. When the EDD kit is full, it is discarded in the trash—not in the recycle bin.
3. Disposing of medications by the nurse requires the presence of a witness, which may be the patient, caregiver or family member.

4. Controlled medications require a witnessed count and disposal.  
Non-controlled medications require a witnessed disposal.
5. The name and prescription number on prescription labels are marked out for privacy/safety.
6. Wrappings are disposed of in the trash.
7. Medications are not disposed of by flushing them down the toilet or drain. The Florida Department of Environmental Protection discourages flushing of medication because this may cause contamination to Florida's aquatic environment. **Note:** The only exceptions are some large-volume intravenous fluids like saline solution and large-volume liquid medication (greater than 2 ounces).
8. Medications from the home are not returned to the pharmacy or removed by anyone in the organization for destruction outside the home.
9. If the caregiver refuses a visit by the nurse at the time of death, the caregiver is instructed by the nurse on how to destroy remaining medications in the home. The reason for refusal is documented.
10. If during the visit the destruction is refused by the caregiver, the nurse informs the caregiver that federal law prohibits the transfer of any drug to any person other than the patient for whom it was prescribed. Refusal by the caregiver to dispose of controlled drugs is documented. A reason for refusal is required and documented.

Reference: CMS, Conditions of Participation for Hospice Care (CoPs), August 4, 2014, 42CFR 418.106 (e)(2)(B and C).



## MEDICAL EQUIPMENT AND SUPPLIES

To meet your physical needs, especially as your condition changes, we provide a wide variety of medical equipment and supplies. Based on your plan of care and discussions with your team, Community Hospice durable medical equipment (DME) staff will deliver medical equipment and supplies to your home. Some of the equipment and supplies we provide include:

- Hospital beds
- Special mattresses
- Oxygen concentrators
- Portable oxygen
- Wheelchairs and walkers
- Nebulizers
- Over-bed tables
- Bedside commodes
- Shower chairs

The Community Hospice DME staff is familiar with the supplies and equipment needed for our patients and are available to provide:

- Compassionate, prompt service
- Equipment setup and installation
- Replenishment of medical supplies, as needed
- Safety requirements and instructions for the use and maintenance of the provided equipment
- Timely pickup of medical equipment
- Prompt response when medical equipment needs maintenance or repair
- A resource for medical equipment questions or concerns

For questions about your medical supplies or equipment, call the 24/7 Patient Priority Line. Our staff will contact DME for you.

## HOME OXYGEN THERAPY

### ***General Rules About Oxygen in the Home***

Oxygen is a chemical element that requires a prescription from your physician for the concentrated form. If your physician has ordered oxygen to help with your breathing, it will require several pieces of equipment—an oxygen concentrator and oxygen cylinder, also called an oxygen tank. The Community Hospice DME team



will deliver, set up, check and train you on the use of this equipment, in coordination with your care team.

Oxygen is for the patient's use only and must be used as ordered, especially following the safety, care and maintenance instructions. Please refer to the complete guidelines about *Home Oxygen Therapy* in this section of the guide.

### **Oxygen Concentrator**

If your Community Hospice physician and nurse have ordered an oxygen concentrator to help with your breathing, the Community Hospice DME team will deliver, set up, check and train you on its use.

#### ***Safety instructions for the oxygen concentrator:***

- The DME team will ask you where to set up the concentrator; however, it cannot be placed in a closet and must be in a well-ventilated area.
- Keep your concentrator at least 12 inches away from any objects, especially flames (including cigarettes), sparks and combustibles, as instructed by the manufacturer.
- DO NOT let anyone smoke or have an open flame when your concentrator is in use.
- Use caution when cooking while using oxygen.
- Never use chemicals of any kind around your concentrator.
- DO NOT use any oils or petroleum-based products (such as Vaseline®) around the tank or when using the concentrator. Mixing oxygen with petroleum-based products can cause problems.
- Plug the concentrator into the grounded wall outlet that was tested by Community Hospice. Do not use a plug that is damaged or shared with other appliances. Do not use an extension cord, unless authorized by the manufacturer or Community Hospice.

***Care and maintenance of the oxygen concentrator:***

- Keep equipment clean and free of dust and dirt by using a damp cloth.
- Always unplug unit when cleaning.
- Make sure that all filters are clean, dry and in their proper places.
- Clean the intake filter (the black foam, if you have one) at least once each week.
- Change the cannula every two weeks unless you have a cold; then change it every week or as needed.
- Keep humidifier bottles clean, and change the humidifier bottle and tubing monthly or as needed.
- If you are not using the concentrator, water should be emptied out of the humidifier bottle to prevent bacteria growth.

**NOTE:** Not every oxygen concentrator comes with a humidifier bottle. If your concentrator has a humidifier bottle and you intend to use it, make sure you fill it with distilled water (if available) before turning on the machine.

***How to operate the oxygen concentrator:***

- Thoroughly read the patient instruction sheet provided by the DME staff.
- Attach all equipment to the concentrator prior to use.
- If you are using the humidifier, empty all water out of the humidifier bottle before you refill it. Use distilled water if available.
- Attach tubing along with cannula to the humidifier using the connector. Connect the humidifier by centering the threaded cap on the humidifier bottle under the threaded outlet tube on the concentrator. Turn the cap on the humidifier bottle until it is tight on the outlet tube.
- Attach the oxygen tube to the nipple outlet. The DME team can provide you with 25 ft. or 50 ft. tubing, and will show you how to merge the tube with cannula or face piece.
- If you are not using the humidifier, leave the humidifier bottle off and attach the cannula to the oxygen outlet. Use the adapter if necessary.
- Turn the power button to the “on” position. When the concentrator is turned on, you will hear a couple of beeps for just a few seconds, and then it should stop beeping. The power light (“OCI”) should illuminate green after 3–5 minutes, or reflect a yellow or red light.
- Turn the flow rate knob to the setting prescribed by your physician and adjust your cannula to a proper fit.

**What to do when the oxygen concentrator is not working:**

- Make sure the concentrator is plugged into the outlet checked by Community Hospice. Check if the plug has a secure fit.
- Make sure the electricity is turned on for the outlet (e.g., not on a light switch).
- Check the reset button.
- Turn the machine off, wait a few seconds, then turn the machine to the “on” position.
- Make sure the flow meter is turned on to the prescribed rate.
- Make sure the oxygen cannula is not pinched off and that it is secure to the humidifier bottle.
- Check that the humidifier bottle is secure and tightly fitted to the unit.
- Replace humidifier bottle with a new one.
- Use your oxygen cylinder at the prescribed liter flow until your concentrator is repaired or replaced.

**Oxygen Concentrator Troubleshooting:**

<b>Problem</b>	<b>Possible Cause(s)</b>	<b>Action</b>
No oxygen seems to be flowing through the system	Cannula or nipple adapter (“Christmas tree” style) is not connected tightly	<p>Place end of cannula into a small glass of water and look for a steady flow of bubbles. If you see bubbles, the oxygen is flowing.</p> <p>If you don’t see bubbles, check to see that the cannula is connected tightly to the oxygen system and that the nipple adapter is screwed on tightly.</p> <p>Check the flow meter; if you see that the ball moves to indicate a decrease in volume, check to see that the cannula is connected tightly to the oxygen system and that the nipple adapter is screwed on tightly.</p>
	Tubing may be kinked	<p>Check tubing for bends, kinks or other obstructions. Stretch out the tubing to make sure nothing is obstructed. If the problem continues, call the 24/7 Patient Priority Line for help.</p>
	Humidifier bottle is not connected	<p>Unscrew the water bottle, checking to make sure the tubing on the inside is not clogged. Then reattach the humidifier bottle, making sure it is connected properly and not cross-threaded.</p>

### Oxygen Concentrator Troubleshooting (continued):

Problem	Possible Cause(s)	Action
Unable to dial the correct flow rate (the small ball in the flow meter doesn't move)	Obstructed humidifier bottle	Disconnect the humidifier bottle; if the ball moves in the flow meter, call the 24/7 Patient Priority Line for a new humidifier bottle.
	Obstruction in tubing	Disconnect tubing; if the ball moves in the flow meter; call the 24/7 Patient Priority Line for a new tube.
	Obstruction in cannula	Disconnect cannula from tubing; if the ball moves in the flow meter; call the 24/7 Patient Priority Line for a new cannula.
Concentrator is not operating and power failure alarm rings	Plug may not be firmly plugged in	Check the plug and try another outlet that you know is working. Try turning on the light switch.
	Concentrator circuit breaker may be turned off	Shut off concentrator at power switch, count to 10, then turn back on to reset the circuit.
	No power at the wall outlet	Check the outlet (fuse or circuit breaker). The wall switch that controls outlet may be switched off. Try another outlet.
	Electrical power outage	Switch to backup system until power is restored.
Temperature light/alarm is on	Unit is overheated	<p>Make sure unit is in a well-ventilated place and that the bed, drapes or walls do not obstruct unit.</p> <p>Check to see if filters on the side of the machine are clean (if your machine has them); if dirty, clean them in warm, soapy water and dry thoroughly.</p> <p>Turn the concentrator off and use backup system for 30 minutes while it cools, then restart the concentrator. If problem persists, call the 24/7 Patient Priority Line immediately.</p>

**Call the 24/7 Patient Priority Line** for assistance if you are still experiencing problems.

## **Oxygen Cylinder (Tank)**

Oxygen prescribed by your physician is stored in an oxygen cylinder or tank.

### ***Safety instructions for the oxygen cylinder (tank):***

- DO NOT let anyone smoke or have an open flame when your concentrator is in use.
- Use caution when cooking while using oxygen.
- Never use chemicals on or around oxygen tanks.
- DO NOT use any oils or petroleum-based products (such as Vaseline®) around the oxygen tank or when using an oxygen cylinder. Mixing oxygen with petroleum-based products can cause problems.
- Always turn off the tank when not in use.

### ***Turning on portable oxygen system:***

Ensure that the regulator is properly installed on the tank by following these steps:

- Using the cylinder wrench provided by DME staff, open the cylinder slowly by turning the nut at the top of the valve COUNTER CLOCKWISE (to the left).
- Check the needle on the pressure gauge. If the needle points to “FULL” or at 2,000 psi, the tank is full.
- Set the flow rate to ensure it is at the prescribed level. If you have any questions, call the 24/7 Patient Priority Line.
- Turn off the oxygen tank by turning the nut on top of the valve CLOCKWISE (to the right) when the patient is finished using the oxygen.

### ***To replace the oxygen cylinder (tank):***

- Remove the nasal cannula from the patient.
- Close the cylinder valve by turning the nut at the top of the tank CLOCKWISE all the way with the cylinder wrench.
- When both gauges are at zero, turn the liter control knob to the OFF position.
- Loosen the regulator with the handle.
- Remove the regulator by lifting it up over the cylinder valve.
- Remove the protective tape from the new tank and slip the regulator over the cylinder valve and neck of the full cylinder. Line up the pins on the regulator with the holes on the neck of the cylinder. Ensure that the gasket is attached to the regulator prior to putting on the new tank.
- Tighten the handle on the regulator.
- Open the cylinder slowly by turning the nut at the top of the valve COUNTER CLOCKWISE with the cylinder wrench.
- Set the flow rate as prescribed by the physician.

### Oxygen Cylinder (Tank) Troubleshooting:

Problem	Possible Cause(s)	Action
No oxygen coming from cannula	Empty cylinder	Check pressure gauge for oxygen contents. If cylinder is empty, remove the regulator and replace with a new cylinder.
Decreased oxygen flow	<ul style="list-style-type: none"> <li>• Pinched or clogged cannula</li> <li>• Cannula has a hole in it</li> <li>• Faulty cannula</li> </ul> <p>Cylinder valve is closed or liter control knob is OFF</p>	<p>Check the regulator to make sure it is on the prescribed liter flow.</p> <p>Place cannula prongs in a clean glass of water. If you see bubbles coming from cannula, the cylinder is working correctly. If you don't see bubbles, replace the cannula and try again. Call the 24/7 Patient Priority Line with questions.</p> <p>Check the cylinder valve to make sure it is open by turning COUNTER CLOCKWISE and check the flow meter to make sure it is on. If issues persist, call the 24/7 Patient Priority Line.</p>
<b>NOTE:</b> If the above actions do not solve the problem, the regulator needs to be replaced. <b>Call the 24/7 Patient Priority Line.</b>		
Oxygen cylinder hisses and is leaking oxygen	<p>Regulator is not tightly attached</p> <p>Faulty gasket</p> <p>Faulty regulator</p>	<p>Turn the oxygen off. Check and tighten connection between the regulator and the cylinder.</p> <p>Check if gasket is attached and fits above the prongs. Call the 24/7 Patient Priority Line for help.</p> <p>Call the 24/7 Patient Priority Line.</p>

**Call the 24/7 Patient Priority Line** with any questions or concerns.

## ***Nebulizer***

Your Community Hospice physician or ARNP may order a nebulizer for breathing treatments. Your nurse will instruct you and your caregiver on the proper way to take breathing treatments using the nebulizer and will help you with the care and use of both the nebulizer and medication.

### ***To set up nebulizer:***

- To use the nebulizer, attach the medication kit to the compressor and add medication to the cup.
- The nebulizer cup can be used for approximately six months (unless it is cracked or leaks).
- The nebulizer cup must be cleaned daily.

### ***To clean the nebulizer cup:***

- Hand wash with warm water and a mild liquid detergent, then air dry.
- Once per week, disinfect the cup with a solution of 50 percent white vinegar and 50 percent water.

### ***Nebulizer Troubleshooting:***

<b>Problem</b>	<b>Possible Cause(s)</b>	<b>Action</b>
Compressor does not turn on	Unit is not plugged in  Compressor motor is broken	Make sure unit is plugged in.  Call the 24/7 Patient Priority Line if motor won't turn on.
Nebulizer cup is not making mist	Nebulizer cup is not properly assembled, cup is cracked or needs cleaning	During the treatment, shake or tap the cup to agitate the medication.  Clean nebulizer cup and reassemble. If the cup is cracked, discard and use a new cup.  If you need a new kit or have questions, call the 24/7 Patient Priority Line.
Medication leaks out of the nebulizer cup	Nebulizer cup is not threaded correctly	Unscrew cap from nebulizer cup and re-assemble.
Compressor unit does not have enough flow	Filter may be dirty  Compressor unit may be worn	Call the 24/7 Patient Priority Line for help.



# DURABLE MEDICAL EQUIPMENT (DME) TROUBLESHOOTING GUIDE

We provide the patient with medical supplies and durable medical equipment (DME) to meet his/her needs. While our caring, trained staff of DME technicians can assist you if a problem arises, this section will help you troubleshoot common mechanical issues.

If you have a problem with equipment that you cannot fix using this troubleshooting guide, please call **the 24/7 Patient Priority Line at 904.407.7300** for assistance.

## ***Hospital Bed***

When the Community Hospice team orders a hospital bed for the patient's safety and comfort, the Community Hospice DME team will provide bed delivery, setup and training. The following information may be helpful for troubleshooting:

### *Hospital Bed Setup and Use:*

- Electric/semi-electric beds must be plugged into a grounded electric outlet.
- Make sure that side rails operate properly and lock into place.
- Check that the mattress is placed in the center of the bed to reduce the risk of the patient slipping between the mattress and the rail.
- Keep the bed wheels locked for safety.
- Adjust the bed's height to reduce bending or stooping, and for transfers to and from a chair or bedside commode.
- Never permit anyone (including pets) under the bed.
- Keep oxygen tubing, blankets, cords, etc., away from moving parts.
- Do not attempt to take the bed apart for any reason.

### **Hospital Bed Troubleshooting:**

<b>Problem</b>	<b>Possible Cause(s)</b>	<b>Action</b>
Head or foot of the bed does not move	May have reached end of drive shaft	Try lowering or raising the bed with the hand control.
The bed height does not move up or down	Hand control not functioning	Check the connection of the hand control with the junction box (located under the foot of the bed) to ensure it is connected. Also make sure the cable is not angled or pinched.
	FOR ELECTRIC BEDS:	
	Bed may not be plugged in	Check that the bed is plugged into the outlet.
	Drive shaft not working	Call the 24/7 Patient Priority line for service.
	FOR SEMI-ELECTRIC BEDS:	
	Hand crank may be dislodged.	Check under the bed to see if the crank shaft/rod is dislodged; if this happens call the 24/7 Patient Priority Line for service.
	Hand crank not working	Ensure pull tubes are properly connected or call the 24/7 Patient Priority Line for a new crank on manual beds.
Unusual sounds, burning smell or unusual movement	Bed needs to be replaced	Unplug the bed and call the 24/7 Patient Priority Line for service.
Bed rolls or does not stay in place	Casters need to be locked	Lock casters; if you aren't sure how to lock the casters, call the 24/7 Patient Priority Line.
Bed ends move in opposite directions	Drive shaft connected to wrong gear box shaft	Call the 24/7 Patient Priority Line for service.
Pressing the hand control causes incorrect action	Motor cable connections not correct	Call the 24/7 Patient Priority Line for service.
Patient receives an electrical tingle or shock while in bed	Junction box malfunction	Unplug bed and call the 24/7 Patient Priority Line for service.

## **Overbed Table**

An overbed table can be convenient for patients who spend time in bed and in a chair. The overbed table can be raised or lowered for ease of use and comfort.

*To raise or lower overbed table:*

- Pull UP on the release lever and adjust the table top to the desired height.
- The table top will adjust to the next locking position when the lever is released and weight is applied to the table top.
- While you can lift the table top assembly to the desired height by pulling on the table top, it is best to pull up on the release lever to adjust.

## **Bedside Commode**

A bedside commode can be helpful for patients who have difficulty walking to the bathroom. The Community Hospice DME team will set up the commode, complete adjustments, train the caregiver on use and review safety information.

*How to adjust bedside commode height:*

- Select the desired height by aligning the snap buttons of each leg extension with the desired adjustment hole in the leg frame.
- Ensure snap buttons are fully engaged into adjustment holes before use.
- When using a raised toilet seat, adjust the height to allow the splash shield to fit into the toilet opening.

*Also for safety:*

- Exert force only straight down in a vertical direction when getting up or down or transferring to prevent the commode from tipping over.
- Sit down on the seat, centered over the opening rather than sitting on the front edge and sliding back.
- If you are using the commode by the bed, make sure you install the bucket that is provided by the DME staff; if using the commode over the toilet bowl, use the splash guards.

If you have any issues or concerns with use of the bedside commode, discuss them with your Community Hospice nurse or **call the 24/7 Patient Priority Line** for help.

**Wheelchair**

- Always lock the wheels before getting in or out of the chair; when possible have someone assist you.
- Ensure that hands and elbows are positioned close to the body when going through doorways.
- Perform basic safety checks as directed by Community Hospice staff.
- Look over all nuts, bolts and hardware for proper tightness; discuss problems with your team.

**Walker**

- Be sure to have the walker adjusted to the proper height before using.
- If you have been instructed by a physical therapist on a proper procedure, follow those instructions explicitly.
- If you are using a walker for the first time, have someone with you until you get used to it.
- Take short steps; be careful not to step all the way into the front of the walker frame.
- Inspect the rubber tips on the walker regularly; immediately replace worn or damaged tips.
- Make sure handgrips are tight; handgrips that turn during use can cause a fall.
- Do not use walkers on stairs.
- If you or your family member is using oxygen, be aware of the tubing and keep it out of the way of the walker wheels.

**Bath and Shower Chair**

- Exert force only straight down when sitting, rising or shifting positions to prevent tipping the seat.
- These items are slip-resistant, but not slip-proof. Initially and periodically, clean the rubber feet or suction cups with alcohol to remove any oil, grease or soap scum to help keep the feet or suction cups effective.
- If the seat is adjustable, be sure that the legs are locked after any adjustment.
- Keep the tub or shower floor clean and free of soap film to prevent slipping.
- A hand-held shower head usually works best with these seats.
- Ask your Community Hospice nurse for help with the use of the chair.



## CHANGING CARE LOCATION

There may be a time when it is necessary for the patient to leave home for a short time because symptoms and pain cannot be controlled at home or you need a respite break. Your nurse can explain the situations where a change in care location may happen.

### ***Transferring to our Inpatient Hospice Center for Caring***

Your nurse will help you with this move and provide further information and advice. The following is a list of suggested items to take along with you:

- Personal items—toothbrush, toothpaste, deodorant, shaving supplies, other toiletries
- Non-medicine items—lip balm, powder, body spray, cell phone
- Medications that your nurse instructs you to bring. Most medications should remain at home. *Keep the medicines in their original labeled container or as directed by your nurse.*
- Special pictures or books
- Favorite pillow or blanket
- Comfortable clothing, pajamas, robe and slippers
- This resource guide

**Note:** Leave valuables at home.

### ***Transferring from Home to an Assisted Living or Long-Term Care Facility***

Sometimes a patient's health declines and he/she needs significantly more help than family caregivers can provide. A skilled nursing or assisted living facility may be an option for patients who need more care for an extended period.

If you are considering this or need help evaluating your needs, your Community Hospice nurse and psychosocial specialist can help with resources and support in making this difficult decision.

Community Hospice staff recognize that the end of life can be a roller coaster of physical, emotional and spiritual issues. There is no right or wrong way to experience this. Our objective is to find out what is most important to you and help you reach these goals.

Just as we tend to your physical needs, we know that you and your loved ones will need emotional support to deal with grief, loss and the changes this experience

brings. We want you and your family to feel confident about your care. Our teams are here to listen, support and guide you and your family. This is your journey, and we honor your wishes, values and needs.

## CARING FOR THE CAREGIVER

Caring for the hospice patient at home can be rewarding; it can also be physically and emotionally exhausting. Taking care of yourself is important.

- Eat at regular times and don't skip meals. Caring for someone who is seriously ill requires a lot of energy.
- Get enough rest. Try to sleep at night for at least six hours and take naps when the patient is sleeping. If you are extremely tired, ask your Community Hospice team for help. They can offer suggestions or may be able to arrange for a volunteer.
- Schedule time for yourself each week. Taking a walk, going grocery shopping, taking a bath or reading a good book can help you clear your head. By taking care of yourself, you are also making sure you can continue to provide the care and attention your loved one needs.
- You do not have to do everything yourself; if someone offers help, take it. Also, it is ok to ask for help with housework, cooking and other household chores.
- Accept help and emotional support. Everyone needs to share their feelings and frustrations with someone who cares. Don't be afraid to cry; it can help you feel better and release stress during a difficult time. Talking to friends and family can help as well. And remember: your Community Hospice team is here to guide you and support you, too.

### ***Your Family Also May Need Help***

Your family is unique, and each person will handle this time in his or her own way. Your Community Hospice team is available to listen to family and friends discuss their feelings and emotions.

There can be relief for the patient, family and friends when old hurts are forgiven, love is reaffirmed and respect for the wishes of the dying patient is expressed. The Community Hospice staff is trained to help in these difficult circumstances and can provide valuable insight and recommendations.

## THE STRESS OF CARING TOO MUCH

For many people, taking care of a loved one who is dying is a new experience. It can lead to mixed feelings, called “compassion fatigue.” Compassion fatigue is a state of emotional, physical and mental exhaustion in which one feels depleted, chronically tired, hopeless and bad, even cynical about oneself, work, life and the state of the world.

Those who constantly and conscientiously care for others, in whatever capacity, are most vulnerable. Even though these activities are voluntary, emotional strains can develop and the once-satisfying relationship can become increasingly stressful. The clash between expectations and reality over time can lead to despair.

### ***Avoiding Compassion Fatigue***

- Be realistic. Do your best to understand the demands of caring for your loved one and ask for help.
- You may feel guilty or angry. It is ok to have negative feelings; be honest and know they are natural and normal.
- Know your limits and be honest about them. Ask family and friends for help, and give them specific tasks. Often people want to help but they just don’t know what to do. Tell them and let them do it. You cannot do it all; accept that everything won’t get done as usual or will be different.
- There are times for humor and laughter. A little laughter and a good joke go a long way to helping everyone feel better; it is ok to laugh and smile.
- Make time for fun by breaking the routine. Remember to enjoy activities that lighten the mood for you and the person you are caring for. Playing cards, watching a movie, or going for a walk can be good for both of you. Speak to your Community Hospice team about other options you may have to take a break. Get a chance to attend a special event or go on a trip. It is ok to take a break from caregiving.
- Seek support if you need it. If you are feeling overwhelmed, resentful, anxious or worried, ask for help and support from family or friends, a support group or your Community Hospice team. You are not alone on the journey—there is help.
- Appreciate yourself. What you are doing is special—you are providing comfort to a loved one and supporting them at a difficult time. Give yourself credit for the work you do—it is special.



## RELAXATION TECHNIQUES

Relaxation can help ease the emotional and physical tension you may feel. It can help control pain as well as decrease anxiety, depression and other symptoms. Learning effective relaxation techniques may take some practice. Consider starting with 10 minutes and then increasing to 20 or 30 minutes. Some people are not comfortable with extended periods of silence. Music and CDs are available to help you with relaxation.

*Take the following into consideration when relaxing:*

- The right environment—make sure you are in a quiet environment, turn off the TV and lower the lights.
- A relaxed posture—if sitting, place your feet flat on the floor with your hands in a comfortable position. If reclining, keep your legs and arms comfortably stretched out.
- Your center and focus—close your eyes to focus attention and avoid distraction; be mindful of the present moment and turn your attention to your breathing.
- With each breath out, imagine any negative thoughts or fears leaving your body and creating room for positive thoughts. With each breath in, picture the positive things in your life, such as your family and/or other loved ones. Imagine these thoughts filling you with peace and love from the top of your head to the tips of your toes.
- When you are ready, gradually begin to notice your surroundings; open your eyes slowly. Take your time and, when ready, continue your day.

If you need more help or tips, ask your Community Hospice psychosocial specialist or chaplain for help.

## SAYING GOOD-BYE

As death nears, it is ok to say good-bye; in fact some find it to be healing. It is a personal time and everyone has his or her own way of saying good-bye. It may be as simple as a loving kiss or squeeze of the hand, or it may be saying, “I love you,” “thank you” or praying. No matter what approach you take, there is no right way or wrong way—just do what works for you.

Be aware that feelings of sadness, anger, helplessness, depression or fear are normal. Talking with a friend or a Community Hospice team member about your feelings can help.

We realize that reading this information and talking about this also may be difficult, but our Community Hospice team is here for you to meet your needs. We want you to be prepared and know what to expect during this time; doing so may alleviate fear and make it possible for you to make the most of whatever time remains.

Your Community Hospice team may also provide a small booklet, *When the Time Comes ... A Caregiver's Guide*, for more information about the dying process.

## THE LAST STAGES

As the human body prepares for the final stage of life, there is a process of “shutting down” that is normal and natural but can be frightening if you are unprepared. We are here with information and support that will help you and your family know what to expect at the time of death so you have the confidence you need to handle the situation with our assistance.

Some of the changes described here will come and go, and may not occur in the order listed or even within the same timeframe. We all live each stage of our life in a unique way.

### *Eating and Drinking*

There may be a decrease in appetite and thirst as the body requires less sustenance. Ice chips or frozen juice may be refreshing, but don't force someone to eat or drink. Properly caring for the mouth is important at this time (see instructions under *Mouth Care* in this section).

### *Breathing Pattern*

Breathing often becomes irregular and may vary from very shallow to very deep. Breathing may stop for 10–30 seconds at a time, with breaths coming only 2–3 times per minute over a long period. This is a natural part of the dying process.

Mucous can gather in the back of the throat and cause a rattling sound that can be disturbing for caregivers to hear. Raising the head of the bed or turning from

side to side may help minimize this sound. Your nurse can help with any breathing issues.

#### *Alertness*

Your loved one may spend more time sleeping and less time talking. It is important to continue conversations, but speak softly and naturally, and ask simple questions that have an easy response, like a nod. It may be comforting to simply share time sitting quietly holding hands.

Your loved one may also appear to be talking to himself/herself and people from the past; this is normal during the dying process.

#### *Restlessness*

A patient may become restless, picking at the air or bedclothes and having difficulty sleeping. A patient who has been bedbound may even try to get out of bed and walk. Your Community Hospice team can help with these symptoms.

#### *Temperature*

Body temperature may increase or decrease at this time. As circulation slows down, arms, legs and the underside of the body may take on a blue-purple color.

#### *Bowel/Bowel Elimination*

Urine output lessens, often becoming darker with a strong odor. Bladder and bowel control may be lost. If this occurs, it is important to keep skin clean and dry.

#### *Activity*

Withdrawal from normal activities may be noticeable. It is not unusual for past interests and hobbies to be ignored. This may include less verbal communication. A patient may experience a brief, unexpected surge of energy and become more alert, asking for a favorite food or activity.

### ***Signs and Symptoms of Approaching Death***

*One to three months prior to death:*

- Decrease in appetite
- Less communication and conversation
- Increase in sleep
- Withdrawal from normal activities

*One to three weeks prior to death:*

- Changes in skin color
- Changes in breathing patterns
- Congestion, “rattling” breathing sounds
- Unable to clear saliva
- Decrease in appetite or refusal to eat
- Changes in body temperature

*Days to hours prior to death:*

- Erratic or irregular breathing pattern
- Restlessness or no activity
- Decreased urine output
- Changes in bowel/bladder function
- May have a surge in energy
- Change in skin color

*At the time of death:*

- Breathing and heartbeat stop and do not resume
- Sometimes there is a release of bowel and/or bladder
- The patient cannot be awakened
- The jaw is relaxed and the mouth may be open
- The eyelids may be open

When death occurs, it is not considered an emergency for a hospice patient. Take the time you need and, if a team member is not there in person, call the Community Hospice 24/7 Patient Priority Line when you are ready. We will help you by providing support by phone, sending someone to your home and contacting the funeral home. If the patient resides in a long-term care or assisted living facility, the facility staff will call Community Hospice.

For more information or if you need additional resources, please visit **CommunityHospice.com**.



# ABOUT ADVANCE CARE PLANNING

## ***The Patient's Right to Decide***

Adults with capacity have the right to make decisions concerning their own health, including the right to choose or refuse medical treatment. A federal government law called the Omnibus Budget Reconciliation Act of 1990<sup>1</sup> allows you to make your health care wishes known to everyone who provides care to you.

When people become unable to make decisions due to a physical or mental change, such as being in a coma or developing dementia, like Alzheimer's disease, they are considered incapacitated. To make sure that an incapacitated person's wishes about health care will still be honored, the Florida Legislature also enacted laws pertaining to health care advance directives (Chapter 765, Florida Statutes).

The law recognizes your right to make an advance care plan. Your advance care plan identifies your wishes about continuing, withholding or withdrawing life-prolonging procedures; designates someone to express your wishes and make treatment decisions if you become incapacitated; and/or indicates your desire to make an anatomical donation after death.

Individuals often do not think about or document health care wishes in advance, and therefore they and their family are forced to make difficult decisions under stressful circumstances. Community Hospice encourages you and your family to discuss the care you would want and make plans that can be easily implemented at the appropriate time. We also provide trained facilitators who can guide you through the conversation and help you complete an advance care plan if you choose.

Whether or not you have an advance care plan, it is important that you inform your nurse of your wishes and any changes you might make while in our care.

<sup>1</sup> In accordance with the Omnibus Budget Reconciliation Act of 1990 and Chapter 745, Florida Statutes, the "Statement of Advance Directives or Living Wills" shall be provided to adults who are being admitted into the Community Hospice program.

By law, hospitals, nursing homes, home health agencies, hospices and health maintenance organizations (HMOs) are required to provide their patients with written information concerning health care advance directives.<sup>2</sup>

<sup>2</sup>The state rules that require this include 58A-2.0232, 59A-3.254, 59A-4.106, 59A-8.0245, and 59A-12.013, Florida Administrative Code. Florida Agency for Health Care Administration (AHCA), Health Care Advance Directives...The Patient's Right to Decide, (Tallahassee: AHCA, 2006)

### **Statement of Advance Directives or Living Wills**

The following is provided to inform you about Florida law regarding “advance directives” or “living wills.”

Under Florida law, every adult has the right to make certain decisions concerning his or her medical treatment.<sup>3</sup> The law also allows for your rights and personal wishes to be honored even if you are too sick to make decisions for yourself.

You have the right, under certain conditions, to decide whether to accept or reject medical treatments, including whether to continue medical treatments and other procedures that would prolong your life artificially.

Your wishes may be spelled out by you in an advance care plan, sometimes called a “living will.” It contains your personal directions about life-prolonging treatments in the case of a serious illness that could cause death.

You also may designate another person, or surrogate, to make decisions for you if you become mentally or physically unable to do so. This surrogate may speak on your behalf and can make health care decisions based on your expressed wishes when your doctor has said you lack capacity.

You can identify and document any limits to the power of the surrogate in making decisions for you.

*(continued on the next page)*

Your health care provider will furnish you with written information about its policy regarding advance directives.

<sup>3</sup>The legal basis for these rights can be found in the Florida Statutes: Life-Prolonging Procedure Act, Chapter 765; Florida Power of Attorney Act, Chapter 709; and Court Appointed Guardianship, Chapter 744; and in the Florida Supreme Court decision on the constitutional right of privacy; GUARDIANSHIP OF ESTELLE BROWNING, 1990.

### ***Community Hospice Policy on Advance Directives and Advance Care Planning***

It is the policy of Community Hospice to involve the patient and family in all health care decisions while in our hospice program.

Community Hospice will not attempt to influence your decisions, nor promote a specific action; nor will Community Hospice take measures to either hasten or postpone death. You may receive care from Community Hospice regardless of whether or not you have executed an advance care plan.

## **TYPES OF ADVANCE CARE PLANNING DOCUMENTS**

### ***Honoring Choices® Florida Advance Care Plan***

Included in the back pocket of this booklet is an advance care plan used in the Northeast Florida community. It was reviewed and approved by the legal departments at local hospitals and adheres to Florida Statutes. *Honoring Choices® Florida*, a program of Community Hospice, is a comprehensive advance care planning program available at no charge to area residents. Facilitators have been trained to guide a conversation about wishes when facing a serious or life-limiting illness. The facilitator also can assist in the completion of the advance care plan. If you choose to complete the document without the guidance of a facilitator, make sure to follow the directions carefully, sign and date it, have it witnessed as directed, and distribute copies as noted on the last page. Advance care planning is about the conversation, not just the document, so make sure to talk to your family, significant others and your health providers, making everyone aware of your wishes to ensure you get the care you want. If you would like a facilitator to meet with you, tell your nurse, your psychosocial specialist, or contact us at **HonoringChoicesFL.com**.



### *Living Will*

A form that documents a person's wishes regarding life-prolonging medical care when he or she is no longer able to make decisions.

### *Health Care Surrogate*

Designates another person to make health care decisions and carry out your wishes when you are no longer able to make them for yourself. This would include decisions concerning life-prolonging treatments such as ventilator or respirator, CPR, feeding tube and IVs.

### *Power of Attorney*

A written document that is immediately effective that allows you to name someone as your agent. The agent steps into your shoes, legally speaking, for the financial powers you have authorized in the power of attorney directive. You can authorize your agent to do such things as sign checks and tax returns, enter into contracts, buy or sell real estate, deposit or withdraw funds, run a business, apply for government benefits, enter into certain trusts, or anything else you do financially for yourself. Your agent's rights end at any time you lack capacity, and you can revoke the power of attorney at any time.

### *Durable Power of Attorney*

Serves the same function as a power of attorney, but also gives your agent the authority to carry out your health care wishes. The agent's authority remains effective even if you become incapacitated, so long as it contains legal language that states something similar to "this durable power of attorney survives incapacity except as otherwise provided under Florida law."

This makes the durable power of attorney an important estate planning tool. If incapacity should strike you, your agent can maintain your financial affairs and carry out your health care wishes until you are again able to do so. That way, your family's needs continue to be provided for, and the risk of financial loss is reduced.

The authority of a durable power of attorney ends at death, and you can revoke your durable power of attorney at any time.

### **About Do Not Resuscitate (DNR) Orders**

A Do Not Resuscitate (DNR) order is an instruction that you want to forgo life-saving measures, such as cardiopulmonary resuscitation (CPR), if you have a medical emergency. The DNR is a specific yellow form available from the Florida Department of Health (DoH).

Community Hospice, another health care provider or your attorney has copies available for your use. You, or your legal representative and your physician must sign the DNR form. More information is available on the DoH website, **FloridaHealth.gov** or **MyFlorida.com** (type DNRO in these websites' search engines) or call **850.245.4440**.

When you are admitted to a hospital, the pre-hospital DNR may be used during your hospital stay, or the hospital may have its own form and procedure for documenting a DNR.

Community Hospice patients are not required to have a DNR in place to receive hospice services.

If you have not signed a DNR and you or your caregiver call 911, you should know what to expect.

Once 911 is called, emergency personnel are required to begin CPR upon arrival if you do not have an original yellow State of Florida DNR form present and completed. This may result in unwanted medical treatment, including placing you on life support. To be valid, the form requires a signature from you or your health care surrogate and your physician.

**Before calling 911 or deciding to go to a hospital, please call the Community Hospice Patient Priority Line first—904.407.7300.**

If you choose to complete a DNR, your physician and family members should each keep copies. Please keep your copy of the DNR form in a location where it is easy for you, your caregiver and other health care professionals to find. Be prepared to provide the original yellow DNR form to emergency medical personnel upon request.

The DNR form always should be with you when you transfer to a different care setting. For example, if you leave your home to go to the hospital, a long-term care or assisted living facility, or your family member's home, you should bring the DNR form with you.

## DECIDING ABOUT ADVANCE CARE PLANNING

### ***When Making a Decision about an Advance Care Plan***

Various organizations, including Community Hospice, make advance care planning documents available. One such document is the *Honoring Choices® Florida* advance care plan developed in collaboration with area hospitals. This document gives you the opportunity to specify the care and treatment you would or would not want when faced with a serious or life-limiting illness. The Honoring Choices advance care plan is in the back pocket of this guide. You can ask your Community Hospice nurse or psychosocial specialist for a copy, or you can find out more at:

**HonoringChoicesFL.com**  
**904.407.7024**

### ***If You Complete an Advance Care Plan***

Talk with the person you designate as your surrogate to make sure he/she accepts the responsibility to carry out your wishes. Discuss your wishes with your surrogate and other family members to make sure everyone knows what you want. Give them copies of your advance care plan and make sure to give your Community Hospice nurse a copy for your medical records.

Set up a file where you keep a copy of your advance care plan. If you keep original documents in a bank safe deposit box, make sure also to keep copies of your advance care plan at home.

Keep a card or note in your wallet that states that you have an advance care plan and where it is located. See the cut-out card in the *Honoring Choices® Florida* document.

If you change your advance care plan, make sure your surrogate, other family members, health care providers and your Community Hospice nurse have the latest copy.

### ***If You Already Have an Advance Care Plan***

Provide your Community Hospice nurse a copy so that your wishes are known and it can be placed in your medical record.

Make sure your family and significant others know you have an advance care plan in place, have copies, know your wishes, and know who you have designated as your surrogate.

Ask to speak with a Community Hospice psychosocial specialist if you have questions about your advance care plan or think you may want to update your plan.

### ***If You Want to Consider Having a DNR Order***

Talk with your Community Hospice nurse about completing this order. See page 109 of this guide for more details.

### ***Organ, Tissue and Full Body Donation***

If you would like to read more about organ and tissue donation to persons in need, you can find information at:

- U.S. Department of Health and Human Services website at **OrganDonor.gov**
- Agency for Health Care Administration website at **AHCA.MyFlorida.com**. Click on “Licensure & Regulation,” “Consumer Resources,” and “Organ & Tissue Donation.”
- Donate Life Florida at **DonateLifeFlorida.org** where you can also register your intent to donate

If you have further questions, you may want to talk with the Community Hospice nurse or psychosocial specialist.

If you want to donate your body after death for medical training and research, there are several options available, with varying costs. In most cases, preregistration with the organization of your choice is available and preferred. Community Hospice staff can assist with identifying the options available to you.

## FINAL ARRANGEMENTS: PLAN AHEAD

Often, people do not think about final arrangements until after a patient has died. Then decisions are required to be made quickly during an emotional and often stressful time. It is beneficial to plan ahead by discussing your wishes with the significant people in your life and writing down how you would like things to be handled.

It is possible to pay in advance for a burial and site, cremation and funeral services via a pre-need contract with a funeral home, crematory or cemetery. Or you can decide in advance to donate your body to science.

## FUNERAL SERVICES

Arranging funeral services can be emotional and difficult. Some think that a viewing at a funeral home and graveside service are the only options available. However you have many choices, from the type of funeral you want to have, to how you want remains transported, to the different kinds of caskets and more.

The Funeral Rule, enforced by the Federal Trade Commission, requires funeral directors to provide you—in person or by phone—with an itemized price list of their services and all products they offer. Funeral expenses can range from \$1,000 to \$10,000.

The first question you will be asked is whether you want a burial or cremation.

### **Burial**

A burial involves decisions regarding viewing, casket, cemetery plot, marker and perpetual care of the site. Memorial services can be held with or without a viewing at your home, house of worship or any other location.

A chapel is available at each Community Hospice Center for Caring for families who wish to use it. There is no fee to use the chapel. Simply notify a Community Hospice team member to help you reserve the chapel.

### **Cremation**

A cremation provides “cremains,” which are the ashes that remain after the body is cremated. Decisions regarding casket and burial are not needed. A burial is still

possible. You may still want to decide on an urn and placement in a cemetery facility. Or the ashes can be appropriately distributed as desired at any time.

### ***Burial at Sea***

Active military personnel and veterans can have their bodies or cremains buried at sea by the U.S. Navy. Contact the U.S. Navy Mortuary Program for this service. Private citizens can arrange for a burial at sea themselves or through a funeral home. The federal Environmental Protection Agency provides guidelines on its website: **[EPA.gov/region4/water/oceans/burial.html](https://www.epa.gov/region4/water/oceans/burial.html)**.

Your Community Hospice psychosocial specialist and chaplain can be helpful in planning and providing resources to help you make the appropriate arrangements based on your beliefs and preferences.

### ***Funeral Home Selection Checklist***

Your Community Hospice psychosocial specialist and chaplain can help you with the process of selecting a funeral home. If possible, visit a number of funeral homes, tour their facilities, meet the staff, and discuss your wishes for the service and your budget.

*Some things you may want to consider:*

- Does the funeral home have enough space to meet your needs?
- What is the funeral home's reputation in the community? Do they have a website for more information?
- Do they use licensed funeral directors, and are they willing to assist you in planning?
- Are pre-arrangements transferable in case your plans change?
- Does the funeral home have affiliations with local cemeteries that can offer savings?
- Can you meet the crematory personnel and witness aspects of the cremation process? Will you receive 100 percent of recoverable ashes?
- Will the funeral director help with arranging religious services and cemetery arrangements?
- Is there a service guarantee?
- Does the cemetery have a veteran's section?

- Does the cemetery have a mausoleum?
- Are aftercare services included? If so, what kind?

### ***The Memorial Service***

Despite the grief and fatigue, spending time with friends and family is a step in the healing process. Sacred texts, poetry and music are commonly used in planning a memorial service. Reflect on your loved one's life; think about his or her values, special events, life's work, hobbies, travels and contributions. Honoring your loved one will help you understand and cope with grief. Some things to consider when planning a service include music selections, readings and symbols of life.

Planning a memorial service often is handled by the immediate survivors. It is also common for the patient to participate in this planning, as well as drafting an obituary. If the patient has reached an understanding and acceptance of his/her disease, planning a memorial service can be helpful for the patient and loved ones. The patient's beliefs and wishes are most important, and every patient and family has the right to plan the services they believe are appropriate.

Community Hospice chaplains or spiritual care volunteers are available to coordinate with and assist your minister, priest, rabbi or other spiritual representative, as well as assist with funerals and memorial services.

It is an honor for us when you choose to pay tribute to the life of your loved one through a gift to Community Hospice. In doing so, you celebrate their legacy and help us continue providing our compassionate care. Ask your Community Hospice nurse for literature about memorial gifts.

## **HANDLING FINANCIAL AND LEGAL TASKS**

Following the death of a loved one, there are many financial and legal tasks that must be addressed soon after the funeral or memorial service.

Many people find it difficult to be certain they have taken care of everything. This detailed checklist can guide you with important administrative and financial decisions after your loss.

## **Administrative Tasks**

### *Death Certificates*

Obtain 15–20 certified copies of the death certificate to use for official notifications to agencies, insurance companies and financial institutions. Funeral homes will provide certificates for a nominal fee. Additional copies can be acquired from the Office of Vital Statistics branch of your local government.

### *Wills and Estates*

Locate the original will and other valuable documents for review with the executor and selected family members for assignment of assets and follow-up.

### *Safe Deposit Box*

Locate and review the contents of safe deposit box(es), as well as other important documents. Review significant items or beneficiary matters with family and attorney. (**Note:** Safe deposit boxes are not immediately accessible after the death if the deceased was the only individual granted access.)

### *Contracts and Lease Agreements*

Gather and review rental or lease agreements for administration and property titles/deeds for name changes and other paperwork.

### *Secure Home or Apartment*

If the patient was living alone, it is advisable to pack, move and secure storage for his/her belongings until they can be sorted.

### *Collection and Copies of Important Documents*

Collect and keep a copy of important documents and information that will be required and helpful in completing administrative tasks, for example:

- Wills, trusts and medical directives
- Birth certificate or legal proof of age, citizenship
- Social Security number
- Veteran's discharge certificates (DD214) and VA claim number
- Marriage license
- Insurance papers and policy numbers, including life, health, accident and property
- Appropriate numbers and access passwords for bank statements, certificates of deposit (CDs), savings bonds, individual retirement accounts (IRAs), 401(k) or 403(b), pensions, other investment accounts



- Titles, deeds, lists of investments, business interests and loan/installment numbers
- Cemetery lot certificate and any documents for pre-arranged funeral services
- Vital statistics needed for burial, insurance claim filing, including state residency, occupation, date/place of birth, parents' names, religious preference
- Most recent income tax paperwork, including W-2 forms

#### *Tax Return(s)*

Seek the advice of an accountant or tax adviser for filing the tax return of the deceased family member for the year of his/her death. Keep the bank statement showing the account balance on the day of the person's death. You may need this information for tax return purposes.

#### *Notifications*

Notify the following to update records:

- Church, synagogue or other house of worship directories
- Alumni and professional associations—fraternal, civic and social
- Insurance—auto, property, homeowners/rental and health
- Automotive—registration/license plate, title, cancellation of driver's license
- Utility companies—telephone (local, long distance, cellular), television (cable, satellite), Internet, electric, gas, water and sewer
- Clerk of the circuit and county courts for deeds and titles to property
- Credit cards and loan banks/companies
- Subscriptions to newspapers, magazines, trade journals and other periodicals
- Landlord and appropriate contract holders

#### ***Helpful Reminders***

Identity theft is a common problem in today's world. Do not give out any important information, such as Social Security and bank account numbers, unless you are confident the person is an official representative of the institution.

If you are the surviving spouse/partner, it is recommended that you delay making long-term decisions, such as a move, sale of a home or investment, until at least one year after the death. Grief and emotional distress following the death of a loved one can impact decision-making and cloud judgment.

Check on life insurance or mortgage insurance clauses that may cancel further premiums/payments upon the death of the insured. Powers of attorney are no longer in force after the death.

### ***Financial Considerations***

#### *Bank Accounts*

Identify available monies/funds, such as checking, bank, credit union, money market and other savings accounts that may have belonged to the patient, to bridge short-term financial needs and make payments on accounts. The executor or trustee will need these funds (with account numbers) to accomplish his/her operational responsibilities.

#### *Investments*

Identify and review trust funds, certificates of deposits (CDs), individual retirement accounts (IRAs), 401(k) or 403(b), pension funds, other retirement and investment funds, securities and additional long-term investments to discuss with family and tax/financial planners for appropriate decisions.

#### *Social Security Information*

If the patient was receiving Social Security benefits, notify the local Social Security office of the death, so these benefits may stop. Recovery of Social Security overpayments can be a complicated process. If you are a surviving spouse, ask about your eligibility for increased benefits, as well as those that any minor children may be entitled to receive.

#### *Benefits for Veterans*

If the patient was a veteran, you may be able to receive some assistance with the funeral, burial plot or other costs. Notify the local or national Veterans Affairs office of the death. The patient's discharge papers are usually needed.

#### *Life Insurance*

Contact the life insurance company about all policies and requirements for fulfilling the contract. Expect to provide the policy number, a certified copy of the death certificate and a completed claim form.

#### *Health Insurance*

Contact the health insurance company or employer about terminating coverage for the patient but continuing coverage for others who may be listed on the policy.

### *Employee Benefits*

If the patient was working or retired, contact the employer for information on pension, 401(k) or 403(b) plans, death benefits, credit unions or incentive/bonus plans. You will likely need a certified copy of the death certificate for each claim.

### *General Household Bills*

Gather and pay regular monthly bills, such as mortgage, rent, utilities and loans. If the funds are not available at the time the payment is due, ask for more time/consideration before the due date of a large payment.

### *Miscellaneous Insurance Policies*

Notify life, automobile, supplemental health and similar insurance companies for possible premium refunds (have policy numbers available).

### *Mortgage and Leasing Agencies*

Notify the mortgage company and house or apartment leasing agency of the death. Review the contract and potential considerations for payouts and penalties.



## DESIGNATION OF HEALTH CARE PROXY

You have been identified as the appropriate individual to make healthcare decisions on the patient's behalf based upon your relationship to the patient and in accordance with Florida Statute 765.401 and Community Hospice Advance Directives Policy and Procedure (Admin .005) as follows:

- ☐ The judicially appointed guardian of the patient who has been authorized to consent to medical treatment;
- ☐ The patient's spouse;
- ☐ An adult child of the patient, or if the patient has more than one adult child, a majority of the adult children who are reasonably available for consultation (document below names and signatures of all children involved);
- ☐ A parent of the patient;
- ☐ An adult sibling of the patient or, if the patient has more than one sibling, a majority of the adult siblings who are reasonably available for consultation (document below names and signatures of all siblings involved);
- ☐ An adult relative of the patient who has exhibited special care and concern for the patient and who has maintained regular contact with the patient and who is familiar with the patient's activities, health, and religious or moral beliefs;
- ☐ A close friend of the patient who has exhibited special care and concern for the patient and who presents an affidavit in accordance with F.S. 765.101(3);
- ☐ A Licensed Clinical Social Worker, not employed by Community Hospice, who is selected in accordance with F.S. 765.401(1)(h).

Your signature below acknowledges your relationship to the patient as selected above, and your willingness to make healthcare decisions on the patient's behalf, and in accordance with the patient's known wishes.

\_\_\_\_\_  
Proxy Name(s)

\_\_\_\_\_  
Daytime Phone

\_\_\_\_\_  
Evening Phone

\_\_\_\_\_  
Proxy Signature(s)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Community Hospice Representative Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
2nd Representative/Witness Signature  
(if designation of proxy is via telephone)

\_\_\_\_\_  
Date

Form #5072, Revised 07/15  
FL License #HPC5024096  
Original: Patient Chart  
Yellow: Proxy

Patient Name \_\_\_\_\_  
Patient Number \_\_\_\_\_





## INFORMED CONSENT

### **Authorization for Treatment**

I hereby request admission to the program of Community Hospice of Northeast Florida, Inc. ("Community Hospice"), and authorize Community Hospice and its medical and professional staff, employees, agents and volunteers to provide care, treatment and services as indicated by my condition upon admission/acceptance into the Community Hospice program.

I understand that the focus of the Community Hospice program is to provide comfort/palliative care rather than cure the underlying disease(s).

I understand that the Community Hospice program promotes the comfort and dignity of patients and addresses the physical, emotional social, psychological and spiritual needs of the patient and family.

I understand that the Community Hospice interdisciplinary team does not take the place of the family or caregiver in caring for the patient, nor does the Community Hospice advanced registered nurse practitioner (ARNP) or Community Hospice physician take the place of the primary physician(s) unless agreed upon by the primary physician and patient/family. The Community Hospice ARNP and/or the Community Hospice physician provide consultation and direction in symptom control as requested by the primary physician(s).

I understand that I have the right to choose who the hospice medical professional will be for my hospice care. I agree to have a Community Hospice nurse practitioner/ARNP assigned to my care as the hospice attending, supervised by the Community Hospice team physician.

- I do not wish to have a Community Hospice nurse practitioner/ARNP as my hospice attending. \_\_\_\_\_  
(Initials)

I understand that I am invited to participate in the interdisciplinary team conferences and participate in discussion(s) about services to assist me and my plan of care.

I have been informed of the services to be provided and agree with the plan of care. I understand that I may revoke the election of hospice care at any time and that to do so I must file a written statement of my intent with Community Hospice.

### **Release of Records / Authorizations**

I authorize release to Community Hospice all medical records and related information to ensure continuity of care and proper reimbursement.

I authorize Community Hospice to release any and all portions of my medical record in order to ensure continuity of care and proper reimbursement.

### **Insurance Benefit, Medicare, Medicaid**

I understand that Medicare, Private Insurance, and Medicaid will be billed directly for the cost of my hospice care. I waive the right to receive services that are for curative purposes related to my terminal illness and related conditions.

I understand that I may be financially responsible for any hospital care, emergency services or medical treatment related to my terminal ill and related conditions that is not provided in a Community Hospice contracted facility and not arranged by Community Hospice.

I certify that the insurance information provided by me is true and correct.

### **Photography / Videography**

I understand that photography and/or videography is used by Community Hospice staff to facilitate coordination of care and treatment. Photos and/or videos are not incorporated into the medical record. I agree to the use of photography/videography as stated.



## INFORMED CONSENT

### **Patient and Family Guidelines - Rights and Responsibilities**

I have received the "Patient and Family Guidelines – Rights and Responsibilities", read it and/or had it explained to me.

### **Advance Directives**

By my signature I verify that I have received the Statement of Advance Directives or Living Wills, read it and/or had it explained to me. In addition, I have received written information about Community Hospice policy regarding Advance Directives. I understand that I am not required to have an Advance Directive in order to receive services from Community Hospice.

### **Notice of Privacy Practices, Protected Health Information**

I have received a copy of the Community Hospice Notice of Privacy Practices.

I understand that Community Hospice maintains a directory of patients enrolled in the hospice program. The purpose of the directory is to be a resource for the patient's family, friends and other significant persons to identify the care location of the patient, general condition, and religious affiliation. I agree to be listed in the directory.

The Protected Health Information (PHI) Security Code assigned to me is \_\_\_\_\_. I understand that I control who receives my PHI Security Code and that persons with the PHI Security Code will have access to my general health information and location. In consideration of this agreement of PHI Security Code, I hereby release Community Hospice and all of its agents, officers, directors and employees from any liability in connection with any unauthorized access or incidental disclosure of my protected health information resulting from self-management of the assigned PHI Security Code.

### **Consent**

I confirm that I have read, or have had read to me, and fully understand this consent document. I acknowledge that my family member(s), significant other(s), friends and I have been given the opportunity to ask questions, and all of our questions have been answered to our satisfaction. I consent to the symptom management, supportive care and case management services as proposed by my physician(s) and Community Hospice.

\_\_\_\_\_  
Patient Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Legal Representative Signature

\_\_\_\_\_  
Relationship to Patient

☐ HCS

☐ HC Proxy

\_\_\_\_\_  
Date

(If) Patient did not sign for self-due to: \_\_\_\_\_

\_\_\_\_\_  
Community Hospice Representative Signature

\_\_\_\_\_  
Date

Page 1 of 2  
Form #5020, Revised 01/16  
FL License # HPC5024096  
Original: Patient Chart  
Yellow: Patient/Family

Patient Name \_\_\_\_\_  
Patient Number \_\_\_\_\_

## PATIENT/FAMILY ELECTION STATEMENT

- It has been explained to me that Community Hospice will provide care for anyone who is qualified and wishes to receive care regardless of their ability to pay.
- It has been explained to me that Medicare, most private insurances and Medicaid, include a "hospice benefit," which includes medical services, medications, needed supplies and equipment as documented on the Hospice Plan of Care.
- I authorize Community Hospice to negotiate with my insurance carrier for care, as well as any and all hospice care.

### **Medicare/Medicaid**

- I understand that Medicare and Medicaid will be billed directly for the cost of my hospice care whether provided within the home, hospital or nursing home. I understand that I will be receiving comfort/palliative care only and that I waive the right to receive services that are for curative purposes related to my terminal illness. Care for all illnesses other than the primary diagnosis and related conditions for which Community Hospice is treating me can be billed to Medicare or Medicaid in the traditional manner.
- I understand that I may withdraw from the Community Hospice program at any time and have my Medicare, Medicaid Insurance Benefits fully restored. I understand that I must revoke the hospice benefit in writing.

### **Medicare Part D**

- The relationship between the Medicare Hospice Benefit and Medicare Part D coverage has been explained to me. I understand that Community Hospice will review my medications after my initial nursing assessment and notify me regarding medications that will be covered by the hospice benefit, medications unrelated to the hospice diagnosis which will be covered under Medicare Part D and medications that I am financially responsible for if I wish to continue them.

### **Private Insurance**

- I hereby authorize that payment be made on my behalf directly to Community Hospice for health insurance benefits otherwise payable to me for the medical benefits allowable under the current insurance policy if applicable. Community Hospice will bill my third party payor as a courtesy to me.
- I understand that I will be responsible for payment of any applicable admission deductibles, coinsurance and non-covered charges due per my contract benefits.

I choose \_\_\_\_\_ as my attending physician/ARNP.  
(Physician/ARNP Name)

Patients Name (Please Print) _____	Patient's Signature _____	Date _____
	<input type="checkbox"/> HCS <input type="checkbox"/> Proxy	

Legal Representative Signature _____	Relationship to Patient _____	Date _____
--------------------------------------	-------------------------------	------------

Patient did not sign for self, due to: \_\_\_\_\_

I hereby witness the above patient/family signature: _____	Community Hospice Representative Signature _____	Date _____
--	--	------------

\_\_\_\_\_  
Effective Date

Form #4648, Revised 10/14  
FL License #HPC5024096  
Original: Medical Records  
Yellow: Patient/Family

Patient Name _____
Patient Number _____







**FLORIDA MEDICAID  
HOSPICE CARE SERVICES  
Election Statement**

- The Florida Medicaid Hospice Care Services program has been explained to me. I have been given the opportunity to discuss the benefits, requirements and limitations of this program and the terms of the election statement. I understand that I will be entitled to elect Medicaid hospice care coverage as long as I am Medicaid eligible and I am certified, by the hospice physician, as being terminally ill.
- I understand that by signing the election statement I am waiving all rights to Medicaid services for the duration of the election of hospice care for the following services:
  1. Hospice care provided by a hospice other than the hospice designated by me (unless provided under arrangements made by the designated hospice); and
  2. Any Medicaid services that are related to the treatment of the condition, or a related condition, for which hospice care was elected or that are equivalent to hospice care with the following exception: services provided by my attending physician (if that physician is not employed by the designated hospice or receiving compensation from the hospice for those services).
- I understand that I may revoke the hospice benefit at any time by signing a statement to that effect, specifying the date when the revocation is to be effective and submitting the statement to the hospice prior to that date. At that time, I understand my rights to other Medicaid services will resume, provided I continue to be Medicaid eligible.
- By signing this statement, I am electing the following hospice to provide me with the services of the Medicaid hospice care program:

Community Hospice of Northeast Florida

**NAME OF HOSPICE**

\_\_\_\_\_  
Signature of Participant or Representative

\_\_\_\_\_  
Date

\_\_\_\_\_  
Election Date

\_\_\_\_\_  
Signature of Hospice Representative

\_\_\_\_\_  
Date

AHCA 5000-21 07/2008





## FACILITY AGREEMENT

This document is an agreement between the facility, the patient/legal representative and the hospice regarding the payment status of the patient. The general, respite, or inpatient contract between the hospice and the facility is kept on file in the facility.

Name of Facility: \_\_\_\_\_ Effective Date: \_\_\_\_\_

The below-named patient has elected to receive **hospice care** under the following payment status:

\_\_\_\_\_ Hospice Medicare: Hospice responsible for all diagnosis-related medications, equipment, treatments, and all hospice services included in the plan of care and approved by hospice.

\_\_\_\_\_ Hospice Medicaid: Hospice responsible for all diagnosis-related medications, equipment, treatments, and all hospice services included in the plan of care and approved by the hospice.

\_\_\_\_\_ Hospice Private Insurance: Hospice responsible for all diagnosis-related medications, equipment, treatments, and all hospice services included in the plan of care and approved by the hospice.

\_\_\_\_\_ Hospice Respite Medicare/Medicaid: Hospice responsible for all diagnosis-related medications, equipment, treatments, and all hospice services included in the plan of care and approved by the hospice. Facility will be reimbursed the current Hospice Medicaid/Medicare Respite rate effective \_\_\_\_\_ to \_\_\_\_\_. (maximum 5 day benefit).

\_\_\_\_\_ Hospice Medicare/Medicaid & Skilled Medicare Part A benefit simultaneously for facility non-related condition of \_\_\_\_\_.

### Facility Diagnosis

\_\_\_\_\_ Hospice GIC: Facility will be reimbursed the contracted Inpatient rate as long as the GIC level of care is medically appropriate.

**NOTE: The facility contracted pharmacy will bill the patient/family for non-related medications provided; including a 5 day respite stay.**

The patient's **Room and Board** payment status (if applicable) will be:

\_\_\_\_\_ Hospice (ICP) Medicaid: # \_\_\_\_\_ Billed by hospice and reimbursed to the facility by hospice at the current facility Medicaid rate less any applicable client responsibility.

\_\_\_\_\_ Hospice (ICP) Medicaid pending (hospice responsibility): Billed by hospice and reimbursed to the facility by hospice at the current facility Medicaid rate regardless of approval status. **(Fax pre-screening to Finance, 904-407-6015)**

\_\_\_\_\_ Hospice (ICP) Medicaid pending prior to hospice election (facility responsibility): Billed by hospice and reimbursed to the facility by hospice at the current facility Medicaid rate and may be recouped if approval is not obtained by facility.

\_\_\_\_\_ Payment for room and board through facility/patient agreement (specify payment source):

Private Pay \_\_\_\_\_ VA \_\_\_\_\_ Diversion Waiver \_\_\_\_\_ Other \_\_\_\_\_

\_\_\_\_\_ Change of patient's hospice status effective \_\_\_\_\_ from above to:

\_\_\_\_\_ Discharge

\_\_\_\_\_ Revocation

Print Facility Representative Name

Facility Representative Signature

Date

Print Patient/Legal Representative Name

Patient/Legal Representative Signature

Date

Print Hospice Representative Name

Hospice Representative Signature

Date

Form #5001A, Revised: 5/11  
FL License #HPC5024096  
Original: Hospice Medical Record  
Yellow: Facility Business Office Manager  
Pink: Patient/Legal Representative

Patient Name \_\_\_\_\_

Patient Number \_\_\_\_\_





## EXPLANATION OF GENERAL INPATIENT CARE AT COMMUNITY HOSPICE CENTERS FOR CARING

Community Hospice of Northeast Florida is mandated by Federal and State Regulations to ensure that all patients/family/loved ones understand prior to admission the following criteria.

While under the care of Community Hospice of Northeast Florida, a patient's condition may require an inpatient level of care. General inpatient care may be required for procedures necessary for pain control or acute symptom management that cannot feasibly be provided in another care setting.

An inpatient stay is a generally short-term intervention that usually lasts one to seven days. During this time, the Community Hospice inpatient staff will work toward managing the patient's symptoms and assessing daily the need for inpatient care.

**When the patient's condition stabilizes and the physician determines that the patient no longer meets the criteria for the inpatient level of care, the patient will be transferred from inpatient status.**

I understand that Community Hospice will assist me in moving my loved one to a more appropriate setting should my loved one stabilize. Alternative settings include: private residence, nursing home, assisted living facility, or other appropriate settings.

I understand that once I have been informed that the patient no longer meets the Medicare/Medicaid guidelines for general inpatient short-term acute care, I will have 24 hours to move my loved one to an appropriate alternative setting or there will be a daily charge incurred.

\_\_\_\_\_  
Please print name of Patient/Patient Representative

\_\_\_\_\_  
Signature of Patient/Patient Representative

\_\_\_\_\_  
Date

Patient Name: \_\_\_\_\_

Patient Number: \_\_\_\_\_

Distribution: Original/White: Medical Record; Yellow: Patient/Caregiver  
Revised: Sept. 2015

Form # 6002  
FL License #HPC5024096



## MEDICATION LOG

**Patient Name:** \_\_\_\_\_

**Patient #:** \_\_\_\_\_

Name of medication	Date started	Date stopped	Dosage and dosage times	Special instructions	Purpose	Size, shape, color



## MEDICATION LOG

**Patient Name:** \_\_\_\_\_ **Patient #:** \_\_\_\_\_

Name of medication	Date started	Date stopped	Dosage and dosage times	Special instructions	Purpose	Size, shape, color

## MEDICATION LOG

**Patient Name:** \_\_\_\_\_

**Patient #:** \_\_\_\_\_

Name of medication	Date started	Date stopped	Dosage and dosage times	Special instructions	Purpose	Size, shape, color

## MEDICATION LOG

**Patient Name:** \_\_\_\_\_ **Patient #:** \_\_\_\_\_

Name of medication	Date started	Date stopped	Dosage and dosage times	Special instructions	Purpose	Size, shape, color

## MEDICATION LOG

**Patient Name:** \_\_\_\_\_

**Patient #:** \_\_\_\_\_

Name of medication	Date started	Date stopped	Dosage and dosage times	Special instructions	Purpose	Size, shape, color

## MEDICATION LOG

**Patient Name:** \_\_\_\_\_ **Patient #:** \_\_\_\_\_

Name of medication	Date started	Date stopped	Dosage and dosage times	Special instructions	Purpose	Size, shape, color

## PAIN CONTROL DIARY

**Patient Name:** \_\_\_\_\_

**Patient #:** \_\_\_\_\_

Pain Scale: NO PAIN		0	1	2	3	4	5	6	7	8	9	10	WORST PAIN YOU CAN IMAGINE	
Date	Time	How severe is the pain? (use scale above)	Where is the pain?	Medication or non-drug method used to control the pain									How severe is the pain after one hour? (use scale above)	Activity at the time of the pain

## PAIN CONTROL DIARY

**Patient Name:** \_\_\_\_\_

**Patient #:** \_\_\_\_\_

Pain Scale: NO PAIN		0	1	2	3	4	5	6	7	8	9	10	WORST PAIN YOU CAN IMAGINE	
Date	Time	How severe is the pain? (use scale above)	Where is the pain?	Medication or non-drug method used to control the pain									How severe is the pain after one hour? (use scale above)	Activity at the time of the pain

## PATIENT INSTRUCTION SHEET

**Patient Name:** \_\_\_\_\_

**Patient #:** \_\_\_\_\_

Date	Instructions	Purpose of the instructions	When to call the Patient Priority Line



## PATIENT INSTRUCTION SHEET

**Patient Name:** \_\_\_\_\_

**Patient #:** \_\_\_\_\_

Date	Instructions	Purpose of the instructions	When to call the Patient Priority Line

## DON'T FORGET TO ASK ABOUT...

**Patient Name:** \_\_\_\_\_

**Patient #:** \_\_\_\_\_

Date	Question	Date	Answer

# DON'T FORGET TO ASK ABOUT...

**Patient Name:** \_\_\_\_\_

**Patient #:** \_\_\_\_\_

Date	Question	Date	Answer

Form#: K:Active Forms/Questions for the Team  
FL License: #H-PC5024096  
Revised: 11/22/2013

4266 Sunbeam Road • Jacksonville, FL 32257  
24/7 Patient Priority Line 904.407.7300 • 877.699.7300 toll free



#### **General Information**

904.268.5200  
800.274.6614 toll free

#### **Referrals & Admissions**

904.407.6500  
866.253.6681 toll free

#### **Charles M. Neviaser Educational Institute**

904.268.5200  
800.274.6614 toll free  
4266 Sunbeam Road, Building 100  
Jacksonville, FL 32257

#### **Community Hospice & Palliative Care Foundation**

904.886.3883  
4266 Sunbeam Road  
Jacksonville, FL 32257

#### **Community Hospice Thrift Shop**

904.998.1718  
ThriftShopJax.com  
  
11173 Beach Boulevard  
Jacksonville, FL 32246  
  
845 Blanding Boulevard  
Orange Park, FL 32065

#### **Inpatient Care Centers:**

##### **Earl B. Hadlow Center for Caring**

4266 Sunbeam Road  
Jacksonville, FL 32257

##### **George and Margaret Morris Center for Caring**

UF Health Jacksonville Pavilion  
555 West 8th Street, 6th Floor  
Jacksonville, FL 32209

##### **Dr. Gaston J. Acosta-Rua Center for Caring**

5450 Ramona Boulevard  
Jacksonville, FL 32205

##### **Anne and Donald McGraw Center for Caring**

Mayo Clinic West Campus  
4715 Worrall Way  
Jacksonville, FL 32224

##### **Bailey Family Center for Caring**

Flagler Hospital Campus  
200 Health Park Boulevard  
St. Augustine, FL 32086

##### **Community Hospice & Palliative Care Center for Caring at St. Vincent's Riverside**

St. Vincent's Medical Center Riverside Campus  
1 Shircliff Way, 4th Floor  
Jacksonville, FL 32204

##### **Jane and Bill Warner Center for Caring**

Baptist Medical Center Nassau  
1348 South 18th Street  
Medical Office Building B  
Fernandina Beach, FL 32034

##### **Community Hospice & Palliative Care Center for Caring at St. Vincent's Southside**

St. Vincent's Medical Center Southside Campus  
4201 Belfort Road  
Jacksonville, FL 32216