

# CHOOSE COMPASSION

# Patient and Caregiver Training Guide

24/7 Patient Priority Line 877.699.7300 toll free

communityhospice.com

#### 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

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# WELCOME

Dear Patient and Family,

Thank you for selecting Community Hospice & Palliative Care as your Compassionate Guide 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 & Palliative Care 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 & Palliative Care 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 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 call our 24/7 Patient Priority Line at 877.699.7300, toll free, day or night.

Sincerely,

Susan Ponder-Stansel

Susan Ponder-Stansel President and Chief Executive Officer

# IMPORTANT NAMES AND NUMBERS

Your hospice care 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 & Palliative Care first.

### 24/7 PATIENT PRIORITY LINE 877.699.7300 toll free Always call Community Hospice & Palliative Care <u>first</u>.

/our Hospice Care Team	
Patient Security Code	
Feam Name	
Physician	
APRN	
Nurse	
Social Worker	
Chaplain	
Hospice Care Aide	
Care Companion	

# GET TO KNOW ME

This information will help your hospice team support you. It will help them get to know you, learn what is important to you and how you like things to be. We invite you, your family and your caregivers to complete this information with as much detail as you want to share with us. Your team is happy to help you complete the "Get to Know Me "page. Please leave this page in your Patient Caregiver Guide for your team to review.

Name: (I prefer to be called)

Things that are important to me: (family, friends, pets or things about my home)

My life so far: (employment, interests, hobbies)

Ways to be helpful and things to avoid: (things that help you or things that upset you)

Things you should know about my spiritual/cultural needs: (important religious or other beliefs)

Food & drink: (likes and dislikes; any help needed with eating, drinking or special diet)

Sleep & rest: (usual routine and what helps you rest or relax)

Personal grooming preferences: (room or water temp, hair care)

Communication, hearing & vision: (what helps you communicate, preferred language, hearing aids, glasses)

Maintaining my independence: (things you like to do for yourself and how we can help)

Anything else: (so that we can provide your best care experience)

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# INTRODUCTION

**HOSPICE CARE PROVIDES COMFORT** for the patient and support for you—the caregiver. We work to manage pain and other symptoms of illness. Staff and trained care companions provide emotional support and can help the whole family explore spiritual questions that often arise when someone is seriously ill. You and your loved one are always in control of the care plan.

#### How Do You Help Someone Who Is Dying?

Hospice workers are often asked that question.

The answer can't be found in techniques or textbooks. Medications and treatments are important, but the real work of hospice is being physically and emotionally present. Sharing the final stage of life's journey with someone who is dying is the most important thing you can do for them. Simply be there.

This caregiver training guide was created by a number of our staff members working as a team. Allow it to provide you with an immediate source of information and to answer many of the questions you might have as you and your loved ones go through this journey.

#### **Confidence In Your Caregiving**

During this stressful time, your hospice care team strives to help you feel more confident in providing care and support to your loved one. We will provide you with medication education, medical information, telephone guidance and ongoing discussions as the disease progresses.

We continually assess both our patient and you, the caregiver. We want to hear what you feel, see and need throughout this time. Your care team will check in frequently asking, "How can we help you feel more confident as a caregiver? What can we help you feel more comfortable doing for your loved one?"

Whatever your questions or concerns, let us know. **We are here for you too.** 

# **Hospice Care Team Members**

Specially qualified and trained team members provide hospice services. The individual receiving care and his or her caregivers are vital members of the care team. Together the team creates a plan that maintains individual dignity and ensures that all physical, emotional and spiritual needs are taken care of.

# Your Hospice Care Team Members

A **Physician** or **Advanced Practice Registered Nurse (APRN)** works together with your team on your treatment. Your 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 physician will work to keep you comfortable and manage any urgent medical symptoms or pain.

A **Hospice Nurse** visits on a regular basis to perform physical assessments, provides education on medications and physical care needs and updates the doctor. Your hospice nurse is a valuable source of knowledge. Your **Social Worker** helps you and your loved ones explore care options, understand legal and financial issues and find emotional support. Social workers are available for individual and family counseling. Our social workers are dedicated to helping the patient and family with the many areas of life impacted by an illness.

**Hospice Care Aides** often have the most frequent interactions with patients; they can be a great source of helpful information. Our hospice care aides are certified nursing assistants and experienced in hospice and palliative care. They offer important personal care and assistance in bathing and dressing. They are also present for emotional support.



# **Frequently Asked Questions About Hospice Care**

#### Q: What is hospice care?

A: Hospice is compassionate, comfort-oriented care for the seriously ill with an emphasis on pain management, symptom control and spiritual and emotional support for the patient and family. A patient qualifies for hospice care when they have a prognosis of months, rather than years, to live.

#### Q: Where can hospice care be provided?

**A:** Anywhere a person calls "home," such as a private home; group home; nursing or assisted living facility. Care can also be provided at one of our hospice centers for caring (refer to page 10) or a hospital.

#### Q: How long can a patient receive hospice care?

A: Indefinitely, if the patient's condition remains appropriate for hospice care at each certification period. A physician certifies that the disease has advanced to the point that the patient has months, rather than years, to live if the illness runs its expected course. After six months, an individual can be re-certified. Patients sometimes experience improved health and do not need continuing hospice support. If their condition deteriorates later, they can be re-admitted. **Chaplains** explore ways to find joy, meaning and purpose in life, even at the end of life. For those who have a religious faith, this may include working closely with your spiritual advisor and faith community. Everyone can benefit from a listening ear, guidance and willingness to explore universal questions, forgiveness and hope.

A **Bereavement Counselor**, trained in supporting those who are grieving, offers supportive services to family members and significant others during the 13 months following a death.

**Specialty Therapists** are also offered as needed. Massage, music, occupational, pet, physical and respiratory therapies treat the entire person—mind, body and spirit. They also 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.



**Care Companion Coordinators** help identify areas in your life where a care companion may offer assistance. They discuss the role of a care companion with the patient and caregiver before asking a care companion to join the team.

**Care Companions** are valuable members of your team and a great source of support. Care companions receive extensive education and are dedicated to maintaining the privacy and dignity of the person receiving care.

Care companions can help in many ways:

- Provide support and presence in the time surrounding death
- Help fulfill a special request or wish to bring fulfillment and comfort to the patient and family
- Provide a friendly visit or relief for a caregiver so they can take a break or go to an appointment
- Offer spiritual care support
- Bring a pet to visit
- Deliver comfort massage or reiki
- Provide support to veterans
- Run errands such as grocery shopping
- Pet Peace of Mind<sup>®</sup>—Offers services to help keep pets at home

# **Frequently Asked Questions About Hospice Care**

#### Q: Who pays for hospice care?

A: Community Hospice & Palliative Care is a Medicare/Medicaid certified hospice program, offering a comprehensive hospice benefit. This benefit includes hospice care team services, medications and treatments related to the terminal illness, medical supplies and durable medical equipment. Many medical insurance companies have similar plans that cover hospice services.

#### Q: Does the patient keep his/her own doctor?

A: Yes, hospice patients may continue to be served by their own physicians. Hospice team members work with each physician, serving as a liaison between physician, patient and family. We have hospital physicians and APRNs on staff. If you wish to change physicians or do not have a primary care physician, and would like one of our hospice physicians or APRNs to oversee your care, notify your team.

# Q: What if the patient moves during hospice care?

**A:** A transfer to another Medicare-certified hospice can be arranged by your hospice care team.

# 24/7 Patient Priority Line

Questions, concerns or problems can often occur during the night or on weekends. Please do not hesitate to call with a question or concern. Be assured that Community Hospice & Palliative Care nursing and/or medical staff are always available through our 24/7 Patient Priority Line at 877.699.7300. The staff will help you over the phone or come to your home if needed.

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.

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 again.

If there is a change in the patient's condition or a medical emergency, call Community Hospice & Palliative Care first. We request that you do not call 911.

# Hospice Care in Assisted Living Communities and Nursing Centers

Assisted living communities and nursing centers have become more common and more popular. And many younger and healthier people are entering senior communities with the intention of aging in place, even as their medical needs change. The medical community refers to all these living environments as "alternative home" settings. They include assisted living, nursing facilities, long-term care centers, group homes or other residential care settings.

People living in long-term care settings, including nursing homes, assisted living facilities or group homes, may receive hospice care. We have dedicated Community Hospice & Palliative Care teams that partner with alternative home staff to care for the individuals who live in them and require hospice care. We provide the same support and care for a resident as we would for a person living in a private home, including additional expertise in pain and symptom management, grief support, ongoing consultation and access to our oncall hospice staff. By working together, we enhance the residential facility's excellent services.

# **Frequently Asked Questions About Hospice Care**

# Q: What if the patient no longer wants or needs hospice services?

A: We will always honor the wishes of the patient or his/her designated representative for care. If services are no longer needed or desired, the patient must sign a discharge form. There are times when a patient's condition stabilizes, and the hospice care team will discuss discharge. Your Community Hospice & Palliative Care team will assist you with a transfer plan that meets your care needs.

#### Q: How does Community Hospice & Palliative Care offer support to caregivers and other loved ones?

A: We provide support from clinical staff, personal care for the patient, professional counseling, music therapy, spiritual care, pharmacy services and more—all of which help caregivers return to the role of spouse, child, parent or friend.

#### HOSPICE CARE IN ASSISTED LIVING COMMUNITIES AND NURSING CENTERS Continued from page 9

If the patient is eligible for a hospice benefit through private insurance, then supplies, equipment and medications needed as a result of the serious illness will be covered.

The charge for room and board is not covered under the Medicare Hospice Benefit. If the patient is living at home, but expects to enter a long-term care facility, the hospice social worker will help locate a facility that works in collaboration with Community Hospice & Palliative Care.

#### **Serving Veterans Since 1979**

We have proudly served veterans and their caregivers since our founding in 1979, and realize they often live with emotional, moral and spiritual wounds that require specialized care. Some veterans hold onto these feelings, which may resurface at the end of their life.

At Community Hospice & Palliative Care, our interdisciplinary care team is trained to focus on a veteran's needs, and those of their caregiver. These feelings are not always associated with combat, so it is important to recognize them and provide quality care to those who chose to serve.

We partner with We Honor Veterans, a program of the National Hospice & Palliative Care Organization and the Department of Veterans Affairs, to honor veterans in our care. Every veteran who self-identifies upon admission to one of our hospice centers for caring is offered a ceremony that includes a Certificate of Honor and an Honored Veteran Pin. If desired, their branch of service flag is placed directly outside their room, identifying them as one of the one percent who chose to serve.

At Community Hospice & Palliative Care we also conduct veteran outreach in homes and long term care facilities. The Community Hospice Veterans Partnership is comprised of veteran leaders who serve as brand ambassadors for our organization. Their role is to educate veterans and their caregivers on end-of-life care through quarterly conferences, meetings, pinning ceremonies, and outreach events.

For the last and the next 40 years, Community Hospice & Palliative Care is proud to serve our veterans and their caregivers.

# Services at Our Hospice Inpatient Centers for Caring

Our centers for caring are 24/7 inpatient centers designed to meet the short-term, acute end-of-life care needs of patients and their families. The goal of inpatient hospice care is to stabilize symptoms quickly and return patients to the place they call home, where they can continue to receive our support.

## Levels of Care Provided at Our Hospice Inpatient Centers for Caring

Your hospice care team, in collaboration with your attending physician, will determine if a change in your loved one's level of care is necessary.

### Pain and Symptom Management General Inpatient

The General Inpatient (GIP) level of care addresses pain or symptoms that cannot be managed at the patient's current residence. Often, patients return to the same residence once pain and symptoms are controlled or optimally managed. If this is not an option, the hospice team will assist in transitioning to an alternate care setting.

Team members will discuss plans for discharge beginning at the time of admission. Anticipated day of discharge will be communicated once the effectiveness of the plan of care has been determined. General Inpatient (GIP) care is billed to Medicare, Medicaid and commercial insurances. Some commercial insurances charge a co-pay for GIP. As long as a patient remains at the GIP level of care, there are no room and board charges.

If a patient needs to remain at the hospice center for care after the hospice team determines that their symptoms are optimally managed, they must be changed to the Routine Home Care level of care. Short-term stays may be approved in order to facilitate a smooth transition to home or another care setting. Room and board charges apply.

General Inpatient care can also be provided in certain hospitals. The option may be offered based on the patient's attending physician recommendation or the goals of care.

#### PAIN AND SYMPTOM MANAGEMENT/GENERAL INPATIENT Continued from page 10

#### **Residential Care**

We at Community Hospice & Palliative Care are committed to providing Residential Care at our Hospice Centers for Caring on a limited basis based on bed availability.

Residential Care assists patients who are unable to care for themselves, have limited capacity or no family caregiving resources or have a limited prognosis.

This level of care may also be approved for patients whose symptoms are controlled or optimally managed but who need a few extra days at the inpatient unit to smoothly transition to another care setting. Room and board charges apply to this level of care.

# **Respite Care**

A patient may be admitted for Respite Care if his or her caregiver needs a short interval of rest or relief from caregiving duties. The caregiver must intend to resume caregiving after the respite admission. A Medicare/Medicaid patient may be admitted for up to five days at the Respite level of care with no room and board charges. Some commercial insurance companies also pay for Respite Care. Occasionally, a patient may need to extend Respite Care beyond five days. Arrangements must be made and approved in advance. Room and board fees apply beginning on day six.

# **Crisis Intervention Care (CIC)**

Crisis Intervention Care (CIC) is a level of care that addresses pain, nausea, shortness of breath or other hard-to-manage symptoms that may require more intense skilled care than can be managed at the patient's current residence with additional skilled nursing intervention. This level of care is meant to be short term. Daily reassessment will ensure that the appropriate level of care is maintained to achieve optimum symptom relief. Your team may, at any point, recommend a transfer to one of our inpatient units if the symptoms persist. This is recommended only if it is no longer feasible to achieve optimum symptom management in the patient's residence.

Once symptoms are controlled, the patient will return to routine hospice care. Crisis Intervention Care is not meant to be a substitute for the patient's caregiver in the home or the hospice care team. It is geared toward managing active, difficult symptoms and caregiver training.

In addition to regular visits by your primary team, you may encounter different staff members while you are receiving this service.

While in your home, our staff will document the care given during the visit and keep other staff members updated on the patient's response to the plan of care.

Our staff will remain awake and alert at all times, conduct themselves as guests in your home and be courteous and respectful at all times.

Our staff will bring their own food and beverages and will not smoke while in your home. Staff members are allowed a 30-minute meal break and up to two 10-minute breaks during an 8–12 hour shift.

# What Can You Do to Maximize the Benefits of Crisis Intervention Care?

Stay involved in your loved one's care. Please be available for visits from your primary team and assist in planning for the patient's care when the current symptoms are managed. Ask questions freely and as often as needed.

You are always welcome to make decisions you feel are in the best interest of the patient, such as not turning in bed, refusing medications, etc. Please discuss these decisions with your primary hospice care team.

If at any time you are not satisfied with a particular staff member in your home, please call your primary team or our 24/7 Patient Priority Line to request a replacement.

# **Patient Travel Information**

There may be occasions when the person receiving care needs to travel outside of our service area. Many hospices across the United States are willing to collaborate on patient care. Please notify your hospice team as soon as possible, at least five business days prior to traveling, so we may contact a hospice and make arrangements for your access to hospice care.

Our policy supports travel outside of our service area for up to 14 consecutive days. If staying longer, please inform your care team. Your care team will make alternate arrangements and provide appropriate forms to be completed.

If the patient's status changes during travel and inpatient care is required, we will assist with the transfer of hospice care.



# Notes



# CARING FOR YOUR LOVED ONE

**YOUR HOSPICE CARE TEAM** will do their utmost to preserve dignity and comfort. What is dignity? Dignity means many things to many different people. It is about self-respect, life history, family, friends, work, hobbies, feelings, hopes, dreams and life lessons—all the things that are most important to our patients; the things that make your loved one unique and special.

Comfort is easier to define. When making a visit, your care team will focus on the patient, noting pain and other symptoms (such as breathing trouble, nausea, weakness or constipation).

It is important to remember that you, the caregiver, are a vital part of the circle of care. Please keep your hospice care team informed of your own emotions and feelings. Your team is here for you.

#### Any question, day or night, call the 24/7 Patient Priority Line 877.699.7300 toll free

# Pain

Managing pain is most important to us. Pain is whatever the person receiving care says it is, existing whenever he/she says it does.

Please be confident that we will believe you and your loved one if you report pain. We will educate you about pain and pain relief measures. Your team will respond quickly to reports of pain.

# **Effective Pain Management**

Pain can be physical, emotional or spiritual. Pain can be caused by many factors such as swelling, nerve damage or progression of a disease. Your team will continually evaluate pain symptoms for your loved one.

Help your loved one try to describe the pain they are feeling. Use words like:

- Sharp
- Constant
- Shooting
- Squeezing
- Dull
- Aching
- Burning

### Try to Rate the Pain. "0" (Zero) Is No Pain. "10" Is the Worst Pain You Can Imagine

(Refer to page 15)

Tell your team what makes the pain better or worse, and how well pain medications are working. We encourage you to write down any and all questions you have. Share them with your care team during visits, or call anytime.

# **Helpful Hints**

- Ask the team about what to expect regarding pain and pain management
- Work with your team to develop a pain management plan
- Report pain when it first begins
- Report any problems that you think the pain medications may be causing, as there may be other options
- Tell your team if you are having any difficulty getting medications or have concerns about them
- Report feelings of anxiety

If your loved one can't communicate, look for the following signs of discomfort and speak for your loved one to your care team.

- Moaning
- Frowning
- Restlessness
- Tension
- Tears

# Helpful Hints for Managing Pain

- Try various relaxation techniques
- Distractions can help—watch a movie, visit with friends, play a game, listen to music
- Soak in a tub, if possible
- Hot or cold packs applied to painful areas
- Try guided imagery
- Apply light massage or touch

# Call the 24/7 Patient Priority Line

- If there is an increase in pain, new pain or discomfort
- If there is no relief from pain
- If there are side effects, which may include constipation, drowsiness and/or nausea
- If you have questions regarding pain management
- If there is a rapid decline or change in your loved one
- If questions arise regarding dosage and/or medication changes

# WONG Baker FACES® Pain Scale



# 0-10 Numeric Pain Scale



# Notes





# **Shortness of Breath**

Oxygen therapy is not a treatment for all types of shortness of breath. Some suggestions for managing shortness of breath are below. Consult the 24/7 Patient Priority Line for other suggestions.

# Helpful Hints If the Patient Is Short of Breath

- Try to stay calm
- Open a window or use a fan directed at the patient's face to create movement of air
- Prop head up in bed/chair
- Apply a cool cloth to face
- Massage
- Yoga breathing (slow breathing in through nose, out through mouth)
- Conserve patient's energy (sit whenever possible)
- Take medication as instructed
- Play soft music or keep room quiet, depending on patient's preference
- If oxygen has been ordered, be sure that it is on

# Call the 24/7 Patient Priority Line

- If distress is caused by shortness of breath
- If fever or moist productive cough is present
- If bluish discoloration of face, nose, fingers or toes is visible

# Fatigue

Fatigue is one of the most commonly experienced symptoms in hospice and palliative care patients. Fatigue is a feeling of extreme exhaustion usually resulting from emotional distress, physical distress or an illness. Signs of fatigue include:

- Increased sleeping
- Lack of appetite
- Not participating in usual activities because of being "just too tired"

# Helpful Hints If the Patient Is Fatigued

- Plan activities for the "most awake" times of the day
- Decrease the number of activities planned for one day
- Change position and location. Avoid staying in bed if able.
- Routinely incorporate activities to restore energy, such as music, meditation, going outdoors
- Consider equipment to help with moving, such as a walker, cane or wheelchair. Relying on equipment will help to conserve energy for other activities of choice.
- Allow caregivers to assist with dressing, fixing meals, eating, shopping, cleaning, laundry, etc., to help conserve energy for other activities of choice
- Rest as needed. Listen to what the body needs.
- Attempt to get uninterrupted hours of sleep and avoid interruptions of sleep routines
- Increase high-protein foods
- Eat small, more frequent meals

# Call the 24/7 Patient Priority Line

- If you notice the suggestions above aren't working
- If the patient is unable to have a restful sleep
- If you are unable to administer medications as prescribed
- If the patient appears unsafe (concerns about falling from extreme fatigue)
- If you would like increased emotional or spiritual support to help with emotional fatigue
- If you or other caregivers are having a hard time coping

# Restlessness

A person may be described as restless if they are unable to rest, concentrate or focus. As restlessness becomes worse it can turn into agitation, and the person is unable to relax given our best efforts. Nearly half of hospice patients become restless during the last 48 hours of life.

# Signs of Restlessness

- Muscle twitching
- Sleeplessness
- Pulling on sheets or clothing
- Trying to get out of bed without a known reason
- Inability to get comfortable
- Repositioning or moving without a known reason
- Fidgeting

# **Helpful Hints**

- Offer frequent reassurance to the person who is agitated
- Play soothing music
- Keep the environment calm (consider decreasing visitors)
- Calmly read a favorite story, poem or letter
- Give a gentle massage
- Distract the person with something familiar, such as photos or a task (folding laundry, art or writing)
- Keep the person safe if they are wandering and check in frequently
- Understand that restlessness may be a sign that death is nearing

# Call the 24/7 Patient Priority Line

- If you notice behaviors or signs listed above
- If you are unable to administer medications as prescribed
- If the patient appears unsafe
- To report what appears to make the restlessness worse (loud noises)
- To report what appears to make the restlessness better
- If you wish to consider spiritual support for the patient
- If the caregiver is having a hard time coping



# **Helpful Relaxation Techniques**

#### Everyone has his or her own way to relax.

By following these simple steps for relaxation, the ability to manage stress and improve breathing will increase.

- Find a place free of distraction and interruptions
- Dim the lights and turn off the television
- Turn off the phone ringer
- Turn on soothing music (optional)
- Lie in bed or sit in a comfortable chair
- Lie or sit quietly, begin to focus on breathing

Naturally, breathing will slow down as you begin to focus on exhaling. As breathing slows, let the weight of your body sink into the chair or bed. Imagine a favorite place. Imagine moving around in this place and notice all the colors, sounds and smells of the surroundings.

Enjoy this place and the feeling of relaxation it brings. Movement is free and breathing is easy in this place. Continue to relax and enjoy the music for a time. It is OK to fall asleep. When ready to return from this place, slowly move fingers and toes and slowly return to an upright position.

# **Sadness and Anxiety**

Sadness is a normal emotional expression, especially when people are sick and at the end of life. Sadness is an expression of grief, unhappiness, loss and sorrow. Even if someone does not verbally express their sadness, sadness can be observed through facial expressions.

#### SADNESS AND ANXIETY Continued from page 17

The hospice team will assess your loved one for sadness and work to address those feelings. They will also help with any physical symptoms to ensure that the sadness is not a result of pain. Often talking about what is making a person sad can relieve some symptoms. Social workers and chaplains are available to listen and assist with emotional support to address any sadness your loved one may be feeling.

Anxiety is a feeling of worry or nervousness. It is not unusual for patients and caregivers to feel anxious. Some people need extra help to address their anxiety. The hospice team will assess the patient and may ask them to rate their feeling of anxiety on a scale from 0 to 10.

#### **Helpful Hints for Managing Anxiety**

- Slow, deep breathing
- Meditation or guided imagery
- Listening to music

• Talking about what is making you feel anxious Sometimes medications are needed. Request an assessment and the team will help determine what will work best for you.

# Seizures

Seizures look like twitches or tremors in the face and/or extremities. Seizures generally last less than a few minutes. Once a seizure has started, it cannot be stopped.

# **D**O

- 🖌 Stay calm
- Protect patient from injury—pad bed rails, remove sharp or hard objects near patient
- Turn head to the side if mouth secretions are present
- Allow for rest after seizure has fully ended

### X DO NOT

- X Force anything between the patient's teeth
- 🗶 Put fingers in the mouth
- Hold down twitching extremities unless it is essential for personal safety

### Call the 24/7 Patient Priority Line

• If the seizure is a new occurrence, is unusual, lasts longer than a few minutes, or results in injury

# **Caring for a Catheter**

A catheter is a tube inserted into the bladder to help drain urine. It has a small balloon that is inflated to keep the tube from falling back out. A catheter may be needed due to increased weakness, loss of bladder control, etc. If a catheter is needed, the hospice nurse will place it and show the caregiver how to care for it.

#### **Helpful Hints**

- Wash your hands before and after handling the catheter
- Check the tubing periodically to see if urine is draining
- Be sure that the tubing is not kinked or bent
- Provide drainage bag care as the nurse instructed
- Empty the drainage bag 1–2 times per day; empty leg bags every 3–4 hours
- Keep the drainage bag below the level of the bladder at all times
- Do not pull or tug on the catheter or tubing
- Cleanse the tubing with soap and water daily and when the tubing gets soiled
- Be sure to begin where the tubing enters the body and work away
- If the patient is pulling on the catheter, put on a pair of adult briefs to hold it more securely in place, keeping it from moving
- When turning the patient from side to side, move the drainage bag from side to side
- Irrigate the catheter if the nurse has instructed you to do so

### Call the 24/7 Patient Priority Line

- If the catheter is not draining
- If the urine has an odor or change in color
- If the patient spikes a fever

# UNDERSTANDING THE ROLE OF MEDICATIONS

Medications come in different forms, including: pills, liquids, inhalants, patches, suppositories and ointments. Medications may be changed into different forms depending on the patient's needs, such as difficulty swallowing. Let your hospice team know if you have less than a seven-day supply of any current medication.

#### Medication ✓ DO

- Read the medication label first
- Administer all medicine exactly as it is written on the prescription or as ordered by the physician, for example "with food"
- Administer routine medication on a regular schedule; timing is very important
- Use breakthrough or in-between medicine as instructed by the hospice nurse and physician to prevent pain from escalating
- Tell your hospice team before stopping or changing medications
- Keep a written schedule and record when, and how often, medication is taken (See Appendix)
- Avoid alcoholic beverages while taking medicine
- Tell your hospice nurse about any over-thecounter drugs, vitamins, mineral supplements or herbal remedies that your loved one is currently taking. Supplements can sometimes interfere with medication.

# X DO NOT

- X Share medications with anyone else
- Crush pills unless directed or instructed by your hospice nurse
- X Take more than the amount that is ordered.

# How to Make Medication Time Easier for Patient and Caregiver

- To make pill swallowing easier, moisten mouth with water or add pills to applesauce or pudding. Some pills may be cut in half.
- If giving a medication rectally, it is best to administer after a bowel movement if possible

- Using a glove, lubricate one finger and insert the medication at least 2/3 of the finger's length
- When using liquid medicine, slightly tilt head upright and slowly pour the medicine down the side of the mouth
- When administering medication under the tongue or between the cheek and gum, moisten the area with two to five drops of water and then place the pills in that area as directed by your hospice care nurse

# **Medication Schedule and Record**

It is helpful to use a medication schedule and record to document all medications given or taken. Inform your care team members where to find the medication schedule so they can make sure your loved one is receiving the correct medication(s) and doses at the right times. Keep the DNRO card with the medication schedule. (See References)

### **Controlled Substances**

Controlled substances are specific medications determined by legal authorities to have a greater need for careful and precise accountability. Examples of controlled substances include many pain medications, like morphine, and some anxiety medications, like Ativan® (lorazepam). 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. The use of controlled substances at Community Hospice & Palliative Care is based on a patient-specific pharmaceutical plan of care, involving critical assessment, careful monitoring, and physician authorization. Any suspected diversion or misuse will be investigated.

### **Comfort Care Kit**

After admission to our program, we 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.

# **Medication Side Effects**

Any medicine can have some side effects, but not all people experience them. People react in different ways to medications and combinations of medications. The doctor or hospice nurse can help your loved one work through any side effects to find the best way to manage symptoms.

### **Sleepiness**

Patients tend to experience fatigue when first starting or increasing a pain medicine. Often after two to three days of following a pain treatment plan, the feeling will pass. The body adjusts to the change. Remember, pain is tiring and with relief of pain, the patient will sleep.

### Constipation

(Having no bowel movement or small, hard stools) Certain medication, especially pain medication, will cause constipation. If your loved one is able, drinking more water and fruit juices may help. The hospice nurse routinely starts with a laxative when a patient is placed on pain medication. Taking laxatives and/or a stool softener routinely each day will help to prevent constipation.

# Call the 24/7 Patient Priority Line

- If there is no bowel movement in two days
- If the patient experiences abdominal pain or cramping, nausea and/or vomiting
- If there are black/tarry or coffee grounds– looking stools, as these may indicate the presence of blood

# Diarrhea

Diarrhea is characterized by loose or watery stools. It may be accompanied by pain and stomach cramping. Diarrhea that does not stop can cause dehydration, weakness, electrolyte imbalances and increased stomach pain.

# **Helpful Hints**

- Try a diet of clear liquids (water, broth, ginger ale), and keep rectal area clean and dry
- Do not give the patient anti-diarrhea medication unless instructed by the hospice nurse
- If diarrhea has stopped for 8 to 12 hours, try dry toast, dry crackers, bananas, rice and clear liquids

# Call the 24/7 Patient Priority Line

• If there is lightheadedness, fever, inability to urinate or continued diarrhea

# Nausea and Vomiting

Your loved one may experience nausea and vomiting for a number of reasons—starting a new pain medicine, an infection, anxiety or a change in their illness. Call your hospice nurse if nausea or vomiting begins; there is medicine to help. The patient should not stop taking the pain medicine without speaking to the hospice nurse first.

However, your loved one should avoid dairy products, heavy meals, fatty foods, strong odors, excessive activity and lying down after eating. These may help digestive issues.

Keep all medicine out of reach of children and pets.

## To Combat Nausea and Vomiting ✓ DO

- Reduce anxiety with meditation, quiet, music or slow breathing techniques
- Administer anti-nausea medication as ordered
- Offer small sips of ginger ale or peppermint tea
- Keep patient still and rested
- Rinse mouth thoroughly after vomiting
- Take ice chips, Popsicles or flavored ice for hydration
- Continue drinking clear liquids for 24 hours (ginger ale, Jell-O, Gatorade) after vomiting
- Add bland foods (crackers, dry toast, dry cereal) after 24 hours following liquid diet

### X DO NOT

- X Eat or drink 1−2 hours after vomiting
- 🗶 Be around strong odors
- 🗶 Eat any spicy or fatty foods

#### Call the 24/7 Patient Priority Line

- If vomiting returns after starting to drink clear liquids
- If vomit is bright red or dark brown
- If constipation continues
- If the patient is unable to swallow
- If you are concerned about medicating your loved one

# **Medication Disposal Policy**

When a patient's prescription medications are no longer needed, it is important to dispose of them properly to avoid harm to others and the environment. Community Hospice & Palliative Care staff assists in the safe and secure disposal of expired, unwanted or unused patient medications, in the patient's home, in accordance with state and federal law. The following are six disposal options and some special disposal instructions for the safe and secure disposal of patient medications:

#### 1. Collection receptacle for drug disposal:

Medications may be disposed of using an Easy Drug Disposal Kit (a tall white plastic canister called an EDD kit), which may be provided by Community Hospice & Palliative Care.

Instructions: Place medications in the EDD kit; add water or liquid medication; shake the canister; and the medications will begin to dissolve. When the EDD kit is full, discard the kit in the trash—not the recycle bin. The following may be placed into the EDD kit for disposal:

- Tablets, capsules, etc.
- Liquids (2 ounces or less)
- Patches—remove from package and place in canister
- Suppositories—remove from wrapping
- Controlled creams—squeeze into canister Exceptions: Large-volume IV solutions and large-volume liquid medications may be disposed of by pouring down the drain. Creams and ointments (non-controlled) may be disposed of in the household trash.
- 2. Disposal in household trash: If no collection receptacle for drug disposal or drug take-back program option is readily available, and there are no disposal instructions on the drug label, then remove medications from their original containers and mix them with an undesirable substance such as used coffee grounds, dirt or kitty litter; place mixture in a sealable bag or container; and throw the bag or container in your household trash.
- 3. Flushing of certain medications: A small number of medications have specific instructions to immediately flush down the toilet when no longer needed and a collection receptacle for drug disposal or drug take-back program option is not readily available. The hospice nurse will instruct in medications to be flushed when applicable.
- 4. Law enforcement take back programs: Check with your local police or sheriff's department for the availability of a "Drug Drop Box" for safe and secure drug disposal.

#### 5. Drug take-back programs

6. Mail-back programs

# MEDICATION DISPOSAL POLICY Continued from page 21

Medications in the patient's home may not be removed by anyone from Community Hospice & Palliative Care for disposal outside of the home.

When hospice staff assists with disposal of a patient's prescription medications, the presence of a witness (who may be the patient, a family member/representative or a caregiver) is required as follows, and the "Disposition of Patient Medications—Home" form is completed and signed by the hospice staff and witness:

- Controlled medications require a witnessed count and disposal
- Non-controlled medications do not require a witnessed disposal

Personal information on the prescription label of empty pill bottles or medication packaging is marked out for privacy and safety before being disposed of in the trash. If the family member/representative declines a visit at the time of patient's death, teaching on the safe disposal of the patient's unused medications in the home is reviewed telephonically with the family member/representative and documented in the patient's clinical record.

If disposal of the patient's unused prescription medications is refused by the family member/ representative, hospice staff informs the family member/representative that federal law prohibits the transfer of any drug to any person other than the patient for whom it was prescribed. Refusal by the family member/representative to dispose of controlled medication(s) and the reason for refusal is documented in the patient's clinical record.

Any question, day or night, call the 24/7 Patient Priority Line 877.699.7300 toll free

#### REFERENCES

1. Controlled Substances Act—Food and Drug Administration: https://www.dea.gov/controlled-substances-act

2. Amendment to the Controlled Substance Act—Bill H.R. 6, the "Substance Use-Disorder Prevention that Promotes Opioid Recovery and Treatment for Patients and Communities Act" or the "SUPPORT for Patients and Communities Act." Subtitle G—Safe Disposal of Unused Medication https://www. congress.gov/bill/115th-congress/house-bill/6

3. Drug Enforcement Agency's (DEA's) Office of Diversion Control's Registration Call Center at 1-800-882-9539 or check the DEA's website at https:// takebackday.dea.gov for authorized collection sites in the area.

4. Florida State Statute 400.6096—Disposal of prescribed controlled substances following the death of a patient in the home.

5. U.S. Food and Drug Administration: "Disposal of Unused Medicines: What You Should Know" at https://www.fda.gov/Drugs/ResourcesForYou/ Consumers/BuyingUsingMedicineSafely/EnsuringSafeUseofMedicine/SafeDisposalofMedicines/ucm186187.htm

6. Medicines Recommended for Disposal by Flushing: https://www.fda.gov/downloads/Drugs/ResourcesForYou/Consumers/BuyingUsingMedicineSafely/ EnsuringSafeUseofMedicine/SafeDisposalofMedicines/UCM588196.pdf

7. Jacksonville Sheriff's Drug Take-Back: http://www.coj.net/departments/sheriffs-office/news-room/jso-news/collection-box-allows-citizens-toanonymously-drop.aspx

8. Florida Department of Environmental Protection (DEP) website: http://www.dep.state.fl.us/waste/categories/medications/

# Notes

# MEDICAL EQUIPMENT AND SUPPLIES

To meet a patient's physical needs, especially as their condition changes, we provide a wide variety of medical equipment and supplies. Based on the plan of care, and discussions with your hospice care team, the durable medical equipment (DME) staff will deliver medical equipment and supplies to the home. 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 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 after the patient is discharged or dies
- Prompt response when medical equipment needs maintenance or repair
- A resource for medical equipment questions or concerns

# OXYGEN USE

The use of oxygen is determined by the doctor and hospice nurse, and it must be used as instructed. The patient or responsible caregiver must sign an Oxygen Agreement Letter when using any oxygen. To notify others that oxygen is in use, you must post "No Smoking/Oxygen in Use" signs that are visible to all visitors. There are two devices provided by your care team that deliver oxygen: oxygen tanks and oxygen concentrators.

# Oxygen Use Can Be Safe If the Following Rules Are Followed:

- Keep all ignition sources (sparks) away from oxygen. Sources of ignition include matches, lighters, candles, hair dryers, electric razors, grinders, gas stoves and appliances.
- The patient should remain at least 10 feet from any source of sparks (radios, TVs, or other electrical equipment)
- Keep a fire extinguisher nearby
- Do not allow the oxygen user or others in the room to smoke where oxygen is turned on
- Avoid use of oil-based lotions, lip balms, petroleum jelly or aerosol sprays. These items are flammable.

# When Using an Oxygen Tank

# **D**O

- Keep tank secured in carrying cart in an upright position
- Store tanks not currently being used on their side and away from heat sources
- Keep valve protection cap in place when tank is not being used
- Store in a well-ventilated area

# X DO NOT

- 🗶 Grab the tank by its valve
- 🗶 Drop the tank or allow tanks to hit each other
- X Store tanks in the trunk of a vehicle

### **Oxygen Concentrator**

An oxygen concentrator is an electrical device that takes the oxygen from the room air and concentrates it so that you are receiving higher oxygen levels. It provides nearly pure oxygen through a nose tube (cannula) or mask. It may use a humidifier bottle attached to the concentrator to filter the room air. An alarm will sound when the concentrator is initially turned on and if it is not operating properly.

# When Using an Oxygen Concentrator

# **V**DO

- Plug directly into a wall outlet
- ✔ Store in an open area
- Always keep sides of the unit a minimum of three inches away from walls, curtains and furniture
- Make sure oxygen tubing is not kinked or bent
- Use only distilled water in the humidifier bottle
- Keep water level in bottle between water fill lines at all times
- Empty humidifier bottle when water level reaches bottom line
- Connect oxygen tubing to humidifier lid
- Change water in bottle every 24 hours to prevent bacterial growth
- Check to make sure water is not building up in tubing

# 🗙 DO NOT

- Plug into outlets that have other appliances plugged into them
- X Use an extension cord
- X Place unit in a closet or enclosed space
- Add fresh distilled water on top of old water; it will contaminate

## Important Oxygen Safety Reminders

# **X DO NOT** SMOKE WHILE OXYGEN IS IN USE.

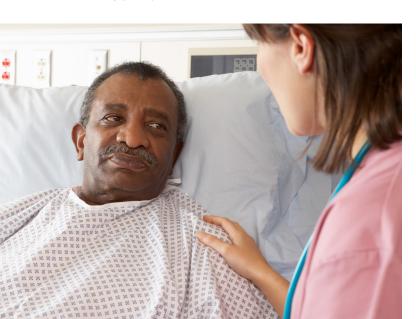
Smoking refers to both tobacco products and smokeless vapor-producing products or devices, such as but not limited to e-cigarettes and hookahs. Smoking devices have heating elements that can serve as an ignition source.

Smoking while using oxygen can cause facial burns, property damage and death. People who smoke while using oxygen pose a threat to themselves, loved ones, caregivers, neighbors and pets.

Many items that would not burn in normal air will ignite when increased oxygen levels are present. When oxygen is used, it creates an oxygen-enriched environment. This lowers the temperature at which everyday household items, such as bedding, furniture, clothing and even human hair, ignite and burn.

#### **At Our Hospice Centers for Caring**

All hospice centers for caring are located on smoke-free campuses. Because of the use of wall oxygen, visitor smoking is prohibited. Designated smoking locations are for patients only. See the center's inpatient handbook for smoking policy information.



# Nasal Cannula (Nose Tube) and Tubing Care

The nasal cannula has two prongs that go gently into the nose. Make sure prongs are curved downward, and bring tubing around each ear to help hold the prongs securely.

Replace nasal cannula or mask if it becomes discolored or cracked. Irritation may occur when using nasal cannula, but can usually be relieved by putting water-based lubricants, such as K-Y Jelly (**do not use Vaseline; it is flammable**) around nasal passages. If tubing causes ear soreness, pad tubing with cotton or gauze around ear area.

### **Helpful Hints**

- Clear tubing attached to the oxygen tank/ concentrator allows oxygen to travel from equipment to patient through a cannula, or facial mask
- Tubing is routinely replaced every three months, along with humidifier bottle, cannula and/or mask; it all can be replaced more frequently, if needed
- Replace tubing if it becomes blocked or kinked

# **Call the Oxygen Provider**

Phone number is printed on oxygen equipment

- When oxygen level meter reads "1"
- When the equipment is not working properly

# What to Do If the Electricity Goes Out

- Stay calm
- Since oxygen concentrators use electricity, you have been provided with a minimum of two tanks in case of power outage
- Take the oxygen tubing that is attached to the concentrator and attach to the oxygen tank, adjust and set oxygen flow rate
- Call the 24/7 Patient Priority Line to report any problems or concerns

# NUTRITION

It is normal for those who are seriously ill to have changes in appetite and in the way they eat and drink. The decline in nutritional status that accompanies end of life can be a cause for concern and stress for the patient and/or their family and caregivers. Food is often considered not only as necessary for survival, but also as a source of caring, nurturing and comfort. However, weight loss and loss of appetite are part of the disease progression and the dying process. 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.

Caregivers can provide care and comfort in non-food related ways. Frequent oral care, small sips of fluid, ointment to the lips and light massage with lotion are all ways to comfort and support the patient at this stage. Try offering food frequently during the day; light meals or smaller portions are usually better tolerated than traditional meal sizes. Offer the majority of fluids between meals, instead of with meals, to prevent feelings of fullness. Arrange mealtimes when your loved one is most rested and active. Do not force your loved one to eat.

The hospice care team will work with everyone to prepare for the nutritional changes that will occur as the disease progresses. The team will explain why the changes are happening, explain care options and offer support along the way.

# Ways to Improve a Poor Appetite

- Your loved one should avoid eating when nauseated or in pain
- Invite others to share mealtimes—socializing makes everything taste better
- Set a pretty table—add candles or flowers, play music, garnish food to make it more pleasing to the eye
- Freshen up hands and face with a warm or cool moist cloth before eating
- Have meal options or food choices available
- Vary food preparation techniques: grill, fry, broil or roast
- Have good-tasting snacks readily available
- If nothing tastes good, hydrate with ice chips or Popsicles
- Use herbs, spices and other seasonings to add flavor

# **Changes in Taste and Smell**

Foods will often taste and smell different as your loved one's illness progresses. This may be due to the illness itself, the medicine or treatments. Even favorite foods may have little or no taste or can taste "off." This can reduce appetite. To combat a poor appetite, have your loved one begin each meal or snack with a clean mouth. Brush teeth and tongue with a soft toothbrush and use a mouth rinse. Frequently rinse mouth between meals with cool water, mint-flavored water, tea or ginger ale.

If your loved one complains about foods such as soups, tomato sauces, casseroles, salad dressings, and gravy tasting salty, try adding sugar. If foods taste too sweet, add a pinch of salt and serve cold. If foods taste too bland, use additional herbs and seasonings and experiment with strong-flavored foods. Have your loved one try alternate bites of different-tasting foods within a meal—for example, a bite of something sweet like pineapple and then a bite of bland cottage cheese. Or try a bite of grilled cheese, then a spoon of tomato soup.

# **Helpful Hints**

- If your loved one complains of a metallic or bitter taste, or of dry mouth, give them lemon drops, mints or gum for relief
- Try serving foods cold or at room temperature, especially meat. This can decrease strong tastes and smells, making them easier to tolerate

#### NUTRITION Continued from page 26

- Avoid foods usually associated with a bitter taste such as red meat, tomatoes, coffee, tea and chocolate
- Add sugar to make food more appealing
- Season foods with tart flavors such as lemon, lime, other citrus, vinegar or sweet and sour sauce
- Don't use metallic containers or metal utensils because it can leave a residual flavor. Plastic, ceramic and glass are neutral.
- Try frozen grapes, oranges, cantaloupe, watermelon, berries and bananas for nutrition and hydration

#### **Difficulty Swallowing**

When a person has difficulty swallowing, there is increased risk of aspiration (taking food or fluids into the lungs) and choking. To decrease this risk, change the texture of foods and/or thickness of fluids. Foods that are of mixed consistency (liquid along with solid) may be difficult to manage in the mouth and therefore increase the risk of aspiration and choking. Examples of mixed-consistency foods are vegetable soup and cold cereal and milk. Also avoid dry, hard, sticky and fibrous foods and any foods with seeds or skins. These types of foods are hard to chew and move around in the mouth, making them more difficult to swallow.

Give your loved one foods that are easy to chew, moist enough to slide down the throat and evenly textured. Soft food is usually well tolerated, but if not, it should be chopped/ground or pureed.

# **X** Foods to Avoid if Swallowing is Difficult

- Foods that crumble and break into pieces (crackers, chips, pretzels, taco shells)
- Foods that consist of small pieces (rice, corn, peas, popcorn, granola, raisins, beans, nuts)
- Food that sticks to the mouth and throat (peanut butter, cream cheese)
- Food that has fibrous parts or seeds (celery, fruits with peels, tough meat)
- Food that is hard to chew (tough meat, whole raw vegetables, hard fresh fruit, bagels)

#### Foods That Are Generally Well Tolerated if Swallowing is Difficult

- Starches: bread, pancakes, waffles, hot cereals, well-cooked pasta, mashed potatoes, muffins, stuffing, lightly toasted bread
- Fruits/vegetables: soft, peeled or pureed fruits and well-cooked vegetables
- Dairy: milkshakes, pudding, custards, ice cream, yogurt, cottage cheese
- Protein: diced, well-cooked meats served with gravies, ground meats and scrambled eggs
- Miscellaneous: soft French fries, cheese pizza, cream soup

#### **Helpful Hints for Mealtime**

- Serve your loved one's meals in a pleasant and relaxing environment; minimize distractions such as TV
- Do not leave your loved one alone while eating
- Allow sufficient time for eating, but avoid long mealtimes so your loved one does not tire
- If your loved one is bed or chair bound, position the patient straight up (hips at a 90-degree angle) with the head slightly forward and the chin down to prevent food from going down the airway
- Serve only one bite at a time and allow time to chew food thoroughly
- If one side of the mouth is stronger, he or she should chew on that side
- Make sure your loved one concentrates on swallowing; patients should not breathe or try to talk until food is completely swallowed
- Coughing can prevent food from going down the airway; the patient should cough as needed
- Avoid using liquids to clear the mouth of food; that may cause choking
- If pocketing of food (food collecting in side of mouth) is a problem, apply external pressure to the affected side of the mouth while your loved one is chewing
- Use pureed baby foods for convenience and add seasonings to enhance flavor
- Use garnishes to make the pureed food look more attractive
- After eating, make sure your loved one remains upright for 20 to 30 minutes
- Use mouth rinse after eating

### **Thickening Liquids**

If swallowing liquids is difficult, they can be thickened by adding a commercial food/liquid thickener to bring them to a consistency that is favorable to the patient. Liquids include juices, soups, coffee and milk. Commercial food/ liquid thickener can be found online or in many drugstores. For more information, ask your hospice nurse about a dietitian consultation.

- Prepare milkshakes in a blender with milk, ice cream or instant breakfast mix
- Mix and thicken soups in a blender with potatoes and/or potato flakes or baby cereal flakes until smooth
- Combine pureed fruit and fruit juice to the consistency of syrup
- Thicken liquids with pureed fruits, yogurt, dried baby cereal, yogurt or pudding
- Place a ripe banana into a blender and add to a milkshake, nutritional supplement or juice
- Add pudding or custard to milk or yogurt

Additional nutrition resources can be found on our website, communityhospice.com.



# **Mouth Care**

Tips for providing mouth care:

- Clean the mouth with toothpaste and soft toothbrush or toothettes
- Use diluted mouthwash for mouth freshness
- Use hard candy, ice chips, Popsicles or frequent sips of water to treat dry mouth
- Spray the mouth with a mister filled with cool water to treat dry mouth (a mixture of 1 tsp. of baking soda in 8 oz. of water into the mouth can also help treat dry mouth)

# Notes

# SAFETY AND PREVENTION

# **Preventing Infection**

Handwashing is the single most important step in the prevention of any infection. Wash your hands with liquid soap and warm water for a full count of 15–20 seconds. Be sure to wash entire hand to above the wrist, between fingers and under fingernails. Rinse well with warm water. Dry hands with a paper towel.

Alcohol-based hand sanitizers may be used when hands are not visibly soiled. Sanitizers may be kept at the bedside for use when a sink isn't close to the patient care area. Apply a small amount to palm of hand and rub hands together, covering all surfaces of hands and fingers until dry.

# Wash Your Hands Before and After

- Giving care to the patient
- Using gloves
- Using the bathroom
- Eating or smoking
- Before preparing meals
- Having contact with any body fluids
- Playing with pets, doing yard work and/or housework
- Returning home from being out
- Having contact with someone who is ill
- Coughing or sneezing

### Influenza (Flu)

This is a highly contagious viral disease that infects the nose, throat and lungs. It is spread from person to person by droplets in the air when the infected person coughs, sneezes or talks. It can also be spread by touching contaminated objects. Symptoms develop 1 to 4 days after exposure and can include fever, headache, dry cough, sore throat, extreme fatigue, runny or stuffy nose and muscle aches. The peak flu season is from late December through March.

### How to Prevent the Flu

It is important that caregivers and family members get a flu shot in October or November. Some patients have weak immune systems that are unable to respond to the flu vaccine, and so they are very susceptible to it. It takes about 2–3 weeks for the body to build antibodies to the vaccine and protect you from the flu. The flu shot lasts approximately 6–9 months and must be repeated every year.

### **Shingles**

Shingles is caused by the same virus that causes chicken pox. After a person recovers from chicken pox, the virus lives on in the body and remains inactive until a patient has a serious illness or trauma that affects the immune system. The virus, when reactivated, causes shingles.

Symptoms of shingles include a tingling feeling on one side of the body, which starts itching and then becomes a rash. Fluid-filled blisters then develop from the rash. These blisters are contagious to caregivers or family members who have not had chicken pox. When these blisters dry and crust over (in about three to five weeks), they are no longer contagious. Visitors and anyone caring for the patient who has not had chicken pox should wait until the patient is no longer contagious before visiting. Check with your doctor immediately.

### **Bloodborne Pathogens**

There are diseases that pose a risk to caregivers, such as Hepatitis B and C and HIV/AIDS. Hepatitis B and C are viruses that cause serious liver disease and are spread through exposure to blood and other body fluids. HIV affects the immune system and is also spread through exposure to blood and other body fluids.

# **Helpful Hints on Preventing Infection**

- Use disposable gloves when in contact with the patient's body fluids (blood, urine, stool, wound drainage)
- Remove gloves and dispose of them in trash immediately after use. Place trash soiled with blood or body fluids in a leakproof plastic bag and place in trash container
- Wipe up body fluid spills as soon as possible, removing all visible debris prior to disinfection
- Use a 10 percent bleach and water solution to disinfect body fluid spills (1 ounce bleach and 9 ounces water). This solution is good for 24 hours only. A fresh solution needs to be made daily. Household disinfectants appropriate to surface being cleaned may also be used in place of bleach solution.
- Air out room when possible
- Place needles, syringes, razors and other sharp objects in a plastic red container. Keep sharps and the red container out of the reach of children.
- Do not share personal care items
- Instruct visitors to wash hands before and after visiting with patient. Request "no visiting" if visitor has a cold or does not feel well.
- If the primary caregiver or other family member is ill, the best choice would be to relieve the caregiver of duties until well again. If this isn't possible, use good handwashing, gloves and a disposable surgical mask to protect the patient.
- Request advice from your hospice team about vaccines and other precautions

# **Prevention of Bleeding**

Patients may be more likely to bleed because of the effects of their illness or medications. Talk with a hospice nurse if any unusual bleeding occurs.

# **Helpful Hints**

- Avoid using sharp objects (knives/ scissors/razors)
- Be careful not to bump into your loved one while you are caring for them
- Use an electric shaver, not a manual razor

- Drink warm fluids and/or eat fruit to help reduce the likelihood of constipation, which can cause bleeding. (See Constipation, page 20)
- Use soft toothbrush, sponge, or "toothette" to prevent gums from bleeding; avoid flossing
- Blow nose gently

# Call the 24/7 Patient Priority Line

- If there is blood in urine, stool, sputum or vomit
- If the patient has a bloody nose (several episodes or one that is not easy to control)
- If the patient has multiple bruises
- If the patient has numerous small, reddishpurple spots under skin
- If bleeding occurs, apply moderate pressure to the area if possible and call your care team

# Preventing the Transport of Bed Bugs

Bed bugs have increasingly become a nuisance throughout the United States. Please report to your hospice team members if bed bugs are suspected or if you know they are present where the patient lives. This will help them to use safety procedures to prevent the bugs' transport outside of the home or facility.

When the care team visits a home or facility where bed bugs are suspected or known, they are required to wear protective shoe covers and coveralls. In some instances, they may be required to carry a change of clothing in sealed bags to change into prior to leaving. The team will bring only supplies or equipment they need for the visit. These will need to be placed on hard surfaces such as a table, chairs without fabric upholstery or similar pieces of furniture. Any equipment or supplies that the team takes with them from the home or facility will be sealed in a plastic bag before they leave.

When a patient must be moved from a home or facility with known or suspected bed bugs to a hospice inpatient unit, hospital, nursing home, assisted living or other location, the hospice care team will bathe the patient and place them in a clean gown provided by the team.

#### PREVENTING THE TRANSPORT OF BED BUGS Continued from page 30

In this situation, patients and family members are not permitted to bring any personal items such as purses, bags, clothing, luggage, hygiene kits, etc. If medications accompany the patient, they will be placed in a sealed plastic bag. Family members accompanying the patient are asked to inspect their clothing prior to accompanying the patient. The hospice care team will notify the transportation company, funeral home and any other agency or service that will have personnel or equipment coming into the home that there is a possible or confirmed infestation.

# **Home Safety**

### **Electrical**

Place electrical cords from medical equipment (bed, oxygen concentrator, etc.) and extension cords out of walkways to prevent tripping or falling. Check extension cords often to make sure they are in good repair. Extension cords should not be overloaded. It is a safer choice to use power strips (surge protectors) or outlet adapters. Keep unused electrical equipment unplugged and place safety covers in unused electrical outlets. Store and use electrical appliances away from water.

### Walkways

Remove as many rugs, runners and mats as possible from areas used by the patient. Secure all loose rugs with double-sided tape or rubber matting to prevent falling. Replace or repair torn or frayed rugs. Keep carpets tacked down. Keep stairs and halls clear and well lit, with well-secured rails on both sides. Patients should wear shoes with treads and avoid using the stairs wearing only socks, loose slippers or smooth-sole shoes.

Outdoor entryways should be well lit and clear of debris, ice, leaves and snow. Provide secure outside step and porch railings. The house address should be clearly visible from the street during the day and night to guide your hospice care team and other visitors.

## Pet Control

For the safety of your hospice team and your family pets, we ask that you move any pets into a secured area prior to team members entering the home. Team members have the right to request that pets be contained and to refuse to enter the home if they are not.

#### Bathroom

Install grab bars and non-skid mats in showers, tubs and toilet areas to help with transferring the patient. Always check the water temperature for the patient before a bath or shower.

### Telephone

Be certain that all cell and cordless phones are charged, and place hospice care team and emergency phone numbers in easy-to-find places near phones. Keep a phone near the patient's bed or chair, within easy reach. If your loved one is alone for all or part of the day, ask a friend, neighbor or other family member to make periodic calls, or consider an emergency monitoring device.

### **Fire Safety**

There should be at least one smoke detector for each level of the home. Develop an evacuation plan that includes evacuating those who need help to walk or who are bedbound. Make a secondary escape plan in case the primary plan cannot be carried out. Include family members, neighbors and/or friends to assist in evacuation if necessary. Be certain to communicate your evacuation plans to everyone involved.

Clear all pathways and keep all exits open and unblocked. If you have a deadbolt, keep the key near the door and let everyone in the household know where to find it. Do not leave fireplaces and space heaters unattended while in use. Fireplaces should have screens or doors which are kept closed. Heaters should have screens or an automatic shutoff device. Kerosene heaters require good room ventilation. Never smoke or have open flames in your home if oxygen is being used or stored. Keep fire extinguishers within reach at home and replace before the expiration date.

# **Emergency Response**

Community Hospice & Palliative Care conducts and participates in periodic emergency preparedness drills in order to test the agency's and community's emergency response plans. Team members will communicate with you in the unlikely event that these could affect you.

In the event of an actual emergency, including natural and man-made disasters, life-threatening situations or utility failures, please contact 911. Please notify Community Hospice & Palliative Care as soon as feasible. Follow the directions of the community emergency response system from the radio or TV.

Team members will be assigned to contact patients and families in affected emergency areas to assist with emergency response. Please contact Community Hospice & Palliative Care to assist in the event that the patient and/or caregiver must be moved or evacuated from their location, or be transported to a hospital or emergency shelter.

#### **Evacuation**

Have an evacuation and backup plan ready. Determine where the patient may be moved to, such as the home of a neighbor or friend. Communicate the plan to everyone involved. Prepare to shelter in place if travel or evacuation is prohibited due to weather or other conditions. Notify Community Hospice & Palliative Care if the patient and/or caregiver needs to change locations.

### **Sheltering in Place**

There are many online resources that can be used to help plan for emergencies that may affect communities for a few days or possibly longer. County and city health departments, emergency management departments and Homeland Security all offer guidance on how to prepare for these situations. Having a seriously ill household member makes these preparations even more important. We encourage you to access these sites and implement plans that meet your particular household situation.

# Some Items to Consider

- Food and water supplies: Three- to five-day supply of water (1 gallon per person per day) and unrefrigerated, ready-to-eat foods
- Medications, patient care supplies and personal care supplies
- Light sources (flashlight, extra batteries)
- Battery-operated radio or TV
- First aid kit

#### **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 social worker 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. Familiarize yourself with evacuation routes from your location to your destination. Evacuation destination choices may include a friend's or relative's home in a safe area or a motel in a safe area. 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 to update your information. We recommend that sheltering in a special needs shelter should always be your last resort.

### **Utility Failures**

In the event of a utility failure, report the problem to the utility company. If the utility failure will require the patient or caregiver to change locations, please notify Community Hospice & Palliative Care.

#### **Power Outage**

If the patient uses a medical device or equipment that requires an electrical source, switch to the backup energy source, if this does not occur automatically. If the patient uses an oxygen concentrator, switch to the backup tanks (see

#### EMERGENCY RESPONSE Continued from page 32

Oxygen Use, page 24). Contact Community Hospice & Palliative Care if patient needs to change location, or notify the oxygen supplier for additional oxygen. If a crisis occurs, call 911.

#### **Gas Leak**

If you know or suspect a natural gas leak, leave the area immediately and go to a safe location. Natural gas has a "rotten egg" smell. Do not do anything that could cause a spark or ignite the gas, such as using electrical devices (telephones, light switches, garage door openers, e-cigarettes, etc.); using open flames (matches, lighters, cooking,

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candles, fireplaces) or starting vehicles. Contact the gas company. Inform the local police and fire departments. Do not re-enter the building until the gas company has given the approval. Contact Community Hospice & Palliative Care if the patient or caregiver needs to change locations.

#### Water Outage/Shortage

If a water outage or shortage occurs, use emergency bottled water supply or purchase bottled water. Follow advisories, notices and directions for using or boiling water. Restrict the use of available water for drinking. Contact Community Hospice & Palliative Care if the patient or caregiver needs to change locations.


# PROVIDING PHYSICAL ASSISTANCE TO YOUR LOVED ONE

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.



### Assistance Using a Bedpan

- 1. When helping someone to use a bedpan, it is always recommended to use gloves
- 2. First explain to the person what you are planning to do
- 3. Lower the bed into a flat position
- 4. Help the person roll to one side in bed
- 5. Place the bedpan squarely under the buttocks
- 6. Roll the person back over on top of the bedpan
- 7. Double check to be sure the bedpan is in the right position
- If able, place the person into a sitting position.
   Place toilet paper or a warm washcloth next to the person.
- 9. Give the person some privacy, but stay close (outside the door) to hear if help is needed
- 10. When they are done, lay their head down and carefully roll the person to one side to remove the bedpan
- 11. Help cleanse the area if assistance is needed and pat dry
- 12. Dispose of waste in the toilet and clean out the bedpan
- 13. Remove gloves and wash hands

#### **Ambulating with Your Loved One**

- 1. Always stand on the person's weaker side when assisting with ambulation
- 2. Place your hands around their waist to guide the person gently and offer support
- If the person should fall, guide them slowly to the ground and sit with them. Keep your hands around their waist to guide their center of gravity to the floor, landing on their bottom.

# **Assistance from Sitting to Standing**

- 1. Assist the person to the edge of the bed or chair
- 2. Face the person with feet shoulder width apart
- Reach under the arms, with their arms on your shoulders, with your knees bent and back straight
- Hug your loved one gently while raising to a standing position; allow them to pull on your shoulders for stability
- 5. Do NOT let go until you are sure the person is stable while standing



#### Assistance Out of a Bed to a Chair

- 1. Have the person scoot to the side of the bed that they will be sitting on
- 2. Raise the head of the bed completely
- Allow the person to rest in the position of having their head elevated to avoid lightheadedness as their body gets used to sitting up
- 4. Bring the person to a sitting position on the side of the bed
- 5. Allow the person to dangle their legs over the side of the bed. Move slowly and allow time for the blood to circulate to avoid lightheadedness as the person changes position.
- 6. Place appropriate footwear on the person's feet to offer stability
- 7. Face the person and place your right foot between the person's feet
- Bend your knees to ensure that you are assisting the person using your legs and not your back
- 9. Grab on to the person's pants or use the draw sheet to help pull the patient to a standing position
- 10. The person should not grab you around your shoulders, as this could injure you. The person can hold on to your waist.
- The person receiving help can push off the side of the bed or hold on to the walker, wheelchair or arms of the chair
- 12. Once standing, pivot slowly, hold on to the person's pants or draw sheet, until the they feel the surface of the chair behind their knees
- 13. Have the person reach both hands backward to the arms of the chair or continue to hold the waist of the caregiver
- 14. Bend your legs to help lower the person as they slowly sit
- 15. Gently guide the person by their waist to sit



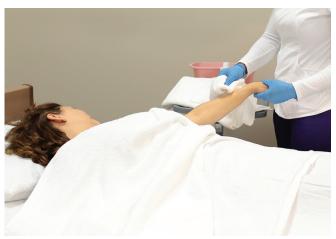
#### **Caring for the Bedbound Patient**

- When caring for a bedbound patient, it is essential to prevent pressure sores or skin tears. Turning or repositioning every two hours is the most effective prevention.
- 2. A natural tendency is to raise someone's feet up; however, it can be harmful to a person's buttocks if their head is raised above 30 degrees and their feet are elevated at the same time. This position will cause skin breakdown to occur on the buttocks from the skin being pulled in opposite directions.
- Another prevention strategy to consider when caring for a bedbound person is to keep the skin clean and dry
- If there are areas that promote sweating, such as on the back, buttocks and under the breasts, clean and pat dry those areas daily. A common "hospice intervention" is to apply antiperspirant under the breasts to help prevent skin breakdown from sweating.



#### Assistance Using a Commode

- When moving with a person, it is essential to explain the purpose, the goal and what you are going to do with the person prior to starting the task
- 2. Ambulate with the person to the commode until the patient feels the surface of the commode behind their knees
- 3. Lower their pants and make sure the lid of the commode is open
- Have the person reach both hands backward to the arms of the commode, or continue to hold the waist of the caregiver
- 5. Bend your legs when you help lower the person as they slowly sit. Be sure they are sitting squarely on the commode. Gently guide the person by their waist to sit.
- 6. Give them toilet paper and a warm washcloth to clean themselves, if they are able
- 7. Allow privacy if needed
- 8. After using the commode, offer hand sanitizer and anything else needed to clean up
- 9. Help to stand after using the commode by first placing their feet in a comfortable position in front of the commode. On a count of three, help to a standing position. Be sure the person gets their bearings prior to taking a step.



#### **Giving a Bed Bath**

- Gather the following supplies if giving a bed bath: wash basin, soap, lotion, washcloths and towels, gloves and clean clothes
- 2. Place warm water in the basin and add soap to the wet washcloth
- 3. Wash, rinse, then dry one area at a time using very little soap (to avoid drying out the skin). Cover each cleaned area with a towel or blanket before moving to the next area. A common strategy is to start with the extremities and wash the trunk last.
- 4. Consider changing the water halfway through washing the patient so that it remains warm
- 5. Check for dry skin and be sure to use moisturizing soap and lotion if you notice this.
- 6. Call the nurse if you notice any red areas that do not go away after several hours
- 7. Keep sheets dry and wrinkle free to prevent pressure sores
- 8. Be sure to turn the person and reposition every two hours to prevent pressure sores

#### **Skin Care**

Keeping the skin moisturized and clean with frequent position changes (every two hours) is important during illness. Specific things to keep in mind about proper skin care:

- If the skin is very dry, use moisturizing soaps and lotions
- After bathing, make sure soap is rinsed off completely and the skin is thoroughly dried
- Avoid rubbing reddened areas
- Everyday bathing may not be appropriate for all patients



#### **Positioning Your Loved One**

- Turning and repositioning a bedbound person should occur to prevent skin breakdown and to maintain general comfort
- 2. If using a hospital bed, start by raising the side rail on the side of the patient that they will be turning toward
- Raise the bed to the top of your hips to avoid bending over the person—bending over could cause back strain, which you always want to avoid
- 4. Remove all pillows
- 5. If they are able, have the person bend their legs to help them roll to the side
- 6. The person should always roll to their weaker side so that the strong arm is pulling their body over
- 7. Ask the person to reach and grab the bed rail to their ability while you gently guide the person on to their side
- Consider placing a pillow, blanket or towel between the knees and ankles to offer additional comfort and prevent bone resting on bone while lying on their side
- 9. Place a pillow behind the back for support and to hold the side-lying position
- 10. There should not be any weight on the shoulder or knees. Be sure bony prominences are protected.
- 11. Raise the head of the bed to about 20 degrees for comfort



#### **Providing Mouth Care**

- Gather the following supplies for mouth care: soft toothbrush, toothpaste, cup of water, dish to spit into. Additional items such as K-Y Jelly to moisturize lips (Vaseline should never be used with oxygen because it is flammable);
   1 tsp of baking soda in 8 oz. water can help with dry mouth.
- 2. Have the patient sit up if possible
- 3. Check for redness or white patches
- 4. Rinse mouth and dentures after meals
- 5. Remove dentures before bed
- 6. Notify the hospice team if you notice white patches on the person's gums, tongue or throat. Also notify the hospice team if the person is having difficulty swallowing.



Pulling Up a Loved One in Bed

\*This is a two-person task.

- 1. If using a hospital bed, start by lowering the side rails
- Raise the bed to the top of your hips to avoid bending over the person—bending over could cause back strain, which you want to avoid
- 3. Lower the head of the bed so that the person is lying flat
- 4. Stand between the hip and shoulder of the person and grab and roll the draw sheet with palms facing down. Be sure the draw sheet is between the nipple line and mid-thigh of the person in bed.
- Have the person bend their knees and dig their heels to help push with their legs to move up in bed if they are able. Remind them to do this on your count to three.
- 6. Remove the pillow from under their head.
- 7. Further direct the person to hug themselves and lower their chin to avoid skin tears
- 8. Both caregivers, turn their front foot forward toward the head of the bed
- 9. Bend at the knees
- 10. On the count of three, pull the person up in bed
- 11. Both people lift at the same time, using leg strength and not your backs, to move the person up in bed
- 12. Gently replace the person in bed, straighten the sheets and flatten any wrinkles that could be uncomfortable for the person to lie on

#### **Changing Bed Sheets**

- 1. If using a hospital bed, start by raising the side rails
- 2. Raise the bed to the top of your hips to avoid bending over the person—bending over could cause back strain, which you want to avoid
- 3. Lower the head of the bed so that the person is lying flat
- 4. Stand between the hip and shoulder of the person. This is where you will grab the draw sheet to move the person onto their side.
- Ask the person to reach and grab the bed rail—if they are able—while you gently guide the person onto their side
- 6. Place the pillow behind the back for support and to hold the side lying position. Position the person's arm out of the way to avoid shoulder discomfort while the person is lying on their side.
- Begin to change the sheets by rolling the used sheets (including the fitted sheet) under the person along the length of the person's body
- Attach the top and bottom corners of the clean fitted sheet and flat sheet. Smooth the clean sheet out under the patient.
- At this time a draw sheet can also be placed under the patient and folded with the clean sheets under the patient. A draw sheet is necessary for someone who is bed bound.
- To complete making the bed with clean sheets, roll the person to their opposite side, helping them to gently roll over the used sheets and newly placed clean sheets
- 11. Once the person is re-positioned on their opposite side with pillows for stability, pull out the used sheets. Place used sheets into the laundry bin.
- 12. Pull the clean sheets tight and attach the final two corners, making sure any wrinkles are flattened

# PHYSICAL ASSISTANCE

#### **Assistive Equipment Use**

Using assistive equipment: walkers, canes, wheelchairs, bath benches and shower seats, etc.

- Assistive equipment should not be used alone until the patient has been shown how to use it properly
- If the patient is unsteady, a walker or cane should not be used without some assistance during walking
- Equipment can be cleaned using soap and water and towel-dried before the next use
- A pad or pillowcase on the wheelchair seat will also help keep it clean
- Make sure the chair or bench is secure and dry in the tub/shower before using the equipment
- Removing all throw rugs will reduce falls

#### Call the 24/7 Patient Priority Line

- If the patient has fallen
- If the equipment is cracked or broken
- If there are any questions about the proper use of the equipment

#### Notes

## CARDIOPULMONARY CARE

#### Chronic Obstructive Pulmonary Disease (COPD)

COPD is the result of lung problems that have developed over a period of many years. It is often associated with severe asthma, chronic bronchitis, or emphysema. Airflow through the lungs has been hindered by inflammation and/or excess mucus, tightening of muscles around the airways or collapse of the airways.

#### Congestive Heart Failure (CHF) or Heart Failure (HF)

When the heart's pumping ability has become too weak to completely empty its chambers, fluid may back up in the lungs, making it very difficult to breathe. Fluid can collect in other body parts as well, causing swelling and discomfort.

#### Fatigue

A common symptom of COPD and CHF/HF is fatigue. It can be difficult for patients to perform everyday tasks such as walking short distances (e.g., down your driveway or around the house) or sitting up at the dinner table. Your hospice team will suggest ways to help conserve energy.

Though rest is helpful, so is exercise. Research shows that the use of large muscle groups in low-intensity exercise can increase energy. Patients who are able should take short walks several times a day when it best suits them. If unable to walk, enjoy other physical activities like knitting or painting. Your hospice team can suggest ideas for physical activities for those who cannot get out of bed.

#### **Breathing Techniques**

There are two breathing techniques that help patients in end-stage cardiopulmonary disease take in more oxygen-rich air. In the first technique, inhale slowly through the nose for two counts, then pucker lips as if blowing out a candle and exhale slowly through the mouth.

In the second technique, sit in a comfortable position with hands resting on the abdomen.

Inhale slowly through the nose, feeling the stomach muscles relax. The chest does not rise. Then, tighten the stomach muscles and exhale slowly through pursed lips.

## Managing Shortness of Breath with Medication

Sometimes it might be suggested by the hospice team that medicine be used to help relieve shortness of breath. Research studies show that the use of an opioid (e.g., morphine) can help reduce exhaustion and relieve a feeling of breathlessness. The hospice team will help explain the use of any medications. At times, the use of a fan may also help lessen the feeling of shortness of breath.

#### Call the 24/7 Patient Priority Line

- If shortness of breath increases
- If use of an inhaler or nebulizer increases
- If the patient feels excessive fatigue
- If mucus secretions increase
- If secretions change color
- If the patient has a fever
- If the patient gains two or more pounds in one day
- If the patient wakes during the night unable to breathe
- If pain in chest, arms, neck, jaw or back is not relieved by current medications

#### Relaxation

Relaxation may be useful to cope with the physical and mental stress of COPD and CHF/HF. The hospice team can provide assistance in relaxation techniques. Some general examples can be found on page 15.

## Spirituality And Patients with COPD/CHF/HF

Exploring spirituality can be helpful emotionally and further enhance relaxation. A Chaplain from your hospice team will contact you to offer to visit. Patients are encouraged to meet the Chaplain. He or she may be helpful in discussing fears, regrets and hopes.

#### **Consider the Following**

- What gives you hope?
- What gives you peace?
- What provides meaning and purpose in your life?

#### Notes

- Talk about accomplishments or regrets
- Think about past coping skills
- Utilize support systems of friends, family, church or synagogue
- Engage in complementary/integrative therapies, such as art, music, massage
- Meditate or use guided imagery
- Identify sources of inspiration and personal growth/satisfaction
- Keep a journal
- Arrange for pastoral care/supportive presence
- Pray, read scripture or sacred texts


# DEMENTIA CARE

Caring for someone with dementia is both rewarding and challenging. It can be particularly difficult if you feel you've lost a connection with the person you love. Community Hospice & Palliative Care is experienced in managing dementia. The following section is designed to assist caregivers in creative caregiving, communication, typical behaviors, safety, medication and other common concerns.

#### **Caring for Yourself**

Studies have shown that many caregivers who are taking care of someone with dementia experience feelings of depression as the disease nears the end (see Caregiver Needs, page 47.)

#### **Disease Progression**

The course of dementia and its progression depend on many factors, including the type of dementia and the overall health of the person. The loss of abilities, the symptoms and behaviors below may indicate late stages of dementia.

#### Cognitive

- Progressive decline in the ability to remember
- Profound confusion and disorientation
- Impaired ability to communicate
- Behavioral changes

#### **Functional**

- Loss of ability to walk or get out of bed independently
- Loss of ability to care for oneself (e.g., dressing, bathing)

#### Nutritional

- Progressive loss of appetite
- Loss of ability to feed oneself
- Weakened capacity to swallow, increasing the risk of choking or aspiration (taking fluid and food into the lungs) and resulting in pneumonia

#### Complications

- Frequent infections, such as pneumonia, urinary tract infections
- Bowel and bladder incontinence
- Skin breakdown related to immobility and incontinence

#### Dementia Symptoms

#### **Behavior Challenges**

Each person with dementia experiences unique changes in behavior. It is important to note that while the changes can be upsetting, the person is not acting this way on purpose. There are underlying reasons, such as pain or illness, noisy environment or overstimulation and unfamiliar or unrecognizable surroundings. Your loved one may be frustrated because communication is difficult or because they can't complete an activity that used to be simple. Any changes in behavior should be discussed with your hospice team so that a comprehensive pain assessment can be done.

People with dementia sometimes become anxious or agitated. Some may even scream, hit or push. Try not to take the aggressive behavior personally. Instead, stay calm and use a soft, reassuring tone. Redirect by engaging in a relaxing activity, such as art or music. Contact your hospice team for more individualized suggestions.

Wandering may not be as much of an issue in late-stage dementia. You may notice the person pacing or walking aimlessly as a result of confusion, restlessness or boredom. For some, it is a way of communicating fears or needs. Make sure the person is getting the right amount of rest, food and drink. Provide reassurance that your loved one is safe. Allow your loved one to wander in areas that are well lit and secure, and take a walk together.

- Keep the area quiet with few distractions
- Make note of what "triggers" the behavior and try to avoid it
- Remove throw rugs and electrical cords that could cause tripping

#### **DEMENTIA SYMPTOMS** Continued from page 42

- Install childproof latches or doorknobs
- Post signs for rooms (e.g., "Bathroom", "Kitchen") to help patient recognize location
- Keep car keys out of sight
- Keep identification on him/her at all times (name, contact phone numbers, address)
- Do not rearrange furniture, as this may add to the patient's confusion

#### Communication

Of all the complications of dementia, the struggle to communicate may be the most troublesome. Memory loss and confusion can create barriers in a once close relationship.

In addition, it is harder to understand the patient's wants and needs. Avoid quizzing your loved one, such as, "Don't you remember?" Instead, offer reminders. Speak in a loving, patient tone. A firm or loud tone and rapid pace of your words may unintentionally express negative attitudes. A relaxed, lower tone of voice conveys patience. Getting a clear response from the patient is not the goal. Communicating to the patient is what is important—not what you get back.

Nonverbal means of communication become increasingly important as the ability to use and convey words diminishes. Body language, gentle touch and eye contact promote ongoing, sensitive communication. Adopting new ways of communication will help maintain the personal relationship and dignity for the person with dementia.

#### **Helpful Hints**

- Look directly at your loved one, approaching him/her from the front
- Use a gentle touch to get attention and provide a physical connection
- Avoid sudden movement, as the patient may startle easily
- Greet your loved one using his/her first name
- Use short, simple words and sentences, or try gestures to help explain
- Give one-step directions

- Speak slowly, clearly and deliberately, but do not talk to him/her like a child
- Ask questions one at a time. Patiently wait for a response, give extra time to respond
- Accept silence. He/she may not talk as much as before
- Eliminate background noise and distractions
- Maintain eye contact at eye level. For example, when he/she is sitting, sit also
- Smiling helps to gain and keep attention

#### **Pain and Discomfort**

Pain can go unrecognized and untreated if the person is not able to express degrees of pain or other symptoms. Part of the comprehensive pain assessment is the PAINAD tool. A member of your hospice team will use it during each visit to determine the person's level of pain. Simple measures such as repositioning or applying a warm compress can help alleviate discomfort.

Medications may be required to improve the level of comfort.

#### Sleeping

Sleep problems are part of normal aging and can be more severe with dementia. Some people with dementia experience "sundowning," which is characterized by increased agitation, restlessness and confusion at dusk and through the night.

This can make it difficult for them to get the sleep needed to function well during the day.

- Limit intake of alcohol and caffeine
- Plan days with interesting activities and increased exposure to daylight
- Establish consistently scheduled times for getting up and going to bed
- Limit daytime napping
- Establish a bedtime routine
- Avoid activities that might be upsetting or cause agitation near bedtime
- Stay calm if your loved one awakens in the middle of the night

#### Eating

Often a person with dementia experiences changes in appetite or ability to eat. While these new eating habits can be distressing for the caregiver, there is a reason, or several reasons, for these changes: loss of interest, inability to chew or swallow, inability to recognize the need to eat, depression or forgetting how to feed oneself can affect eating. Talk to your hospice team about well-balanced meals. You may be able to replace meals with highcalorie snacks or shakes.

#### **Helpful Hints**

- Reduce the size of helpings or offer finger foods
- Alter the flavor of foods, since tastes may have changed
- Chop or puree food to ease chewing and swallowing
- Avoid exposure to large groups of people during mealtime
- Offer one food at a time with the correct utensil to avoid confusion

#### Overeating

In some instances, the person cannot sense fullness or differentiate nutritious foods from foods that are less healthy. He/she may not understand the timing of meals, or the differences between breakfast, lunch, dinner and snacks, or is unable to recall when he last ate. In this case, it is better to limit access to snacks, especially sugary ones, which has a negative effect on the individual's mobility.

#### **Helpful Hints**

- Provide alternatives that satisfy the sweet tooth but are lower in calories, such as sugar-free Jell-O and pudding, cookies containing dried fruit and/or nuts, low-sugar candies
- Introduce stimulating activities throughout the day that help keep focus away from food and eating
- Maintain a consistent meal schedule
- Look for snacks the individual may have hidden

#### Swallowing

Difficulties in eating can be the result of physical conditions and an indication that dementia is in late stage. Dysphagia (trouble managing oral secretions or drooling), weakness of a voluntary cough or swallow and involuntary tongue thrusts are common. Changes may also occur in voice quality/tone (hoarseness/moist sound), frequent throat clearing, poor oral hygiene and weight loss or dehydration.

During mealtimes, the person may experience uncoordinated chewing or swallowing, multiple swallows for each mouthful, pocketing of food in the cheeks, or coughing or sneezing during/ following eating. If the patient experiences pain or discomfort in the throat or chest when swallowing, or has a sensation of food/liquid "sticking" in the throat, something special may have to be done with the head or neck to ease swallowing. In such cases, eating may be so strenuous as to cause fatigue, changes in respiratory patterns, hoarseness or reflux. Talk with your hospice care team if you feel swallowing has become challenging.

#### **Helpful Hints**

- Keep eating and speaking separate to avoid choking
- Avoid lengthy mealtimes which contribute to fatigue
- Do not leave your loved one alone while eating
- Refer to the Nutrition section on page 26 for more tips and suggestions

#### **Interventions in Dementia Care**

#### **Feeding Tube**

Sometimes the placement of a feeding tube is considered. Studies have shown that artificial nutrition and hydration do not improve the comfort, functional status or quality of life for people with dementia. This is an individual choice for each family, and your hospice care team will respect your wishes.

#### INTERVENTIONS IN DEMENTIA CARE Continued from page 44

Not surprisingly, caregivers are often concerned the person on a feeding tube is experiencing hunger; however, other patients at the end of life who are able to communicate say they experience little or no hunger or thirst. Mouth swabs or ice chips can alleviate what little discomfort they might feel.

#### **Medications**

Upon your enrollment with Community Hospice & Palliative Care, your hospice nurse and pharmacist reviewed all current medications with the primary physician. Medications are evaluated for effectiveness and appropriateness. New medicines may be ordered depending on the stage of dementia. In general, medications meant to slow the advancement of Alzheimer's dementia are no longer appropriate during the end stages of the illness when the focus of care is on comfort. All medications will be discussed with the caregiver(s) by the hospice team.

Refer to the Medication section on page 19 for more information or ask your hospice team.

#### **Creative Caregiving**

Before beginning any personal care for the person, such as bathing, consider any sensitivity and try to accommodate it. Think about how and when the person with dementia prefers to wash. For instance, is your loved one a late riser? Does your loved one prefer to wash before bed? Have the room ready, warm and free of drafts. Begin in the least sensitive area of the body, such as hands and arms. Wash hair last or at a separate time. Give him/her something to hold, like a sponge ball, and play soothing music or sing familiar songs.

#### **Connecting with Music**

Music is very effective in easing the stresses of dementia. The rhythm, pitch and melody can stimulate different parts of the brain. It can soothe an agitated person, relieve anxiety and decrease pain. It provides a means of reminiscence and can bring a sense of belonging and spirituality. Furthermore, music helps a person with dementia express himself/herself. By singing or playing a familiar song, you may notice changes in facial expression, increased eye contact, vocal activity and movement.

#### **Helpful Hints**

- Sing or hum a familiar song, such as "Take Me Out to the Ball Game," while completing personal care like bathing or changing the sheets
- During mealtimes, play familiar recorded music with a relaxed tempo
- Rock or move gently to the person's favorite music, for example, big band or classical music
- Listen to music from concerts the person attended and tell stories about it
- Play quiet music at bedtime

Please Note: Listening to music may conjure both positive and negative memories and feelings. If certain types of music cause agitation, try another song or stop the music altogether.

#### The Importance of Touch

For a person with dementia, touch can be a way of connecting and avoiding a feeling of isolation. A gentle touch provides a feeling of acceptance and a sense of well-being. This improved emotional experience reduces fatigue, anxiety, depression and tension. Use gentle touch when you need to get his/her attention.

- Be clear about your intention, telling him/ her exactly what you are going to do
- Massage over clothing, which may be more comfortable for people with neuropathy
- Do not require him/her to change positions
- Avoid areas of skin with irritation or inflammation
- Keep in mind that skin may be fragile and sensitive

#### **Spirituality and People with Dementia**

Spirituality is a connection to a higher sense of self and purpose in life. It is expressed in our beliefs, actions, faith and relationships with God or a higher power, self, others and creation. For persons with end-stage dementia, the emotional aspects of spirituality are more meaningful, as they connect with the heart rather than the intellect. Reaffirm that life is precious, love is available and joy in the present moment is possible.

#### **Helpful Hints**

- Stimulate the senses, especially through scents, visuals and textures
- Play videos of scenes of nature with soft calming sounds
- Read familiar prayers, poems, stories, Scripture passages and blessings
- View TV programs of religious/spiritual nature
- Listen to music or sing religious hymns
- Make religious or cultural rituals or services available
- Give the patient a spiritual symbol to hold
- Provide an exercise in guided imagery or meditation
- Get help from your local religious figure of your faith
- Celebrate religious/cultural holidays that are a family tradition

#### Unique Grief and Loss for Dementia Caregivers

Feelings of grief and loss can occur at any time when caring for a person with dementia—not just in the final stages. You may feel angry about the disease, saddened that you struggle to communicate, or depressed that your loved one is no longer the person you knew. Focusing on the person now, versus the loss of memory or abilities, may help lessen the grief that you are experiencing.

When the end is near, caregivers deal with what is referred to as anticipatory grief—the reality that death is inevitable. Previously, the end seemed to be far in the future, but changes in the last few months have made the end of the journey closer. There is no right or wrong way to grieve, no calendar and no magic solutions. Feelings of grief are very powerful and often misunderstood. It is physically and emotionally draining, and operates on a timeline all its own. You may experience physical, emotional, intellectual, behavioral and spiritual reactions.

Talking about the grief you are experiencing sometimes requires help from a professional.

Community Hospice & Palliative Care offers bereavement services that provide support, encouragement, education and resources for 13 months following the death of your loved one.

#### Notes

# **CAREGIVER NEEDS**

Although you may not consider yourself a caregiver, you are one. A caregiver is anyone who cares for a seriously ill person. A caregiver is most often a family member or close friend.

Caring for someone can be both rewarding and stressful. It is not unusual to experience a variety of feelings at this time. These feelings are neither good nor bad. They are your feelings, and they may affect your life and well-being during the time you are providing care.

Over the years, we have learned from caregivers that caring for someone with a serious illness is a lifechanging process. They have taught us that even in the midst of hurt and sadness, there are chances to learn, grow and heal.

Being a caregiver can be a valuable time to create lasting and positive memories together. Unexpectedly, you may find you experience other rewards as a caregiver. You may feel a sense of inner peace or a stronger sense of self-worth. You and your loved one may find moments of joy and laughter in your time together; your relationship may become more emotionally intimate. You may find time to close some unfinished business with your loved one, saying things that you need to say.

#### Caregiver Responsibilities Can Feel Overwhelming. Please Be Aware Of:

- Excessive fatigue
- Fear of the unknown
- A loss of control
- A loss of "normal" activities
- Financial worries
- Social isolation
- Emotional challenges
- Feelings of obligation, guilt or resentment
- Difficulty making plans

#### In Order to Effectively Care for Another Person, You Need to Care for Yourself

- Establish visiting hours so that you can have both support and privacy
- Select a family member or friend to be in charge of relating updates by phone or email to others who are concerned
- Educate yourself about the condition and the decline of the person receiving care. Information is empowering
- Realize that no one can be all things to all people. You may not be able to live up to everyone's expectations. Try not to dwell on negative comments.

Maintaining good health is a priority. Get enough rest, eat properly and exercise. Identifying your needs as a caregiver is the first step toward taking care of yourself and the person receiving care. Your hospice care team can also help you discover additional resources.

#### What would you like to have help with?

- Household chores
- Shopping
- Getting through the night
- Personal care

### What questions do you have about providing care?

- How do I administer medication?
- If my loved one is not eating, is starvation a possibility?
- Can we take outings?
- What worries you?
- Is my loved one suffering and in pain?
- What are my financial obligations?

We are committed to answering your questions, supporting your needs and helping you feel more at peace and confident in caring for your loved one.

# FINAL DAYS

Everyone's life is unique, and so is everyone's journey toward death. This is a difficult time because you may not know what to expect during the patient's final days. Your Hospice team will do everything they can to help you feel more confident and less anxious. Your team can provide bedside education on things you can do or say to help your loved one as he or she receives care. We want you to be informed and prepared, but it is natural to feel confused and upset. Be kind and gentle to yourself.

From one to three months before death, it is common for a person's world to focus inward. There is a shift away from the outer, more social world. This is not a withdrawal of love from you, but a need to focus energy inward. Your presence is very important.

There may be differences in how family members and friends respond. Some may wish to have private time with their loved one. Some may wish to provide personal care. Your hospice team will support you and help you do what feels right for you.

#### Signs and Symptoms of Approaching Death

As the patient prepares for the final stage of life, you may notice physical changes taking place. Not all of these signs will appear at the same time, and some may never appear at all. Please let us know what you see and experience. Your hospice team will help you identify these changes and support you through this difficult time. You have undertaken the most precious service by caring for a loved one. It is our desire to be present with you and the patient during the last days and hours. Call the 24/7 Patient Priority Line and your hospice team will coordinate this supportive presence for you. Signs and symptoms you may see include:

- Decreased need for food and drink, and difficulty swallowing because the body functions are gradually slowing down. The mouth may become dry and will need to be kept moist. The patient will not experience hunger.
- Sleeping a lot or difficult to arouse is a result of a change in the body's metabolism. Try to spend more time with the patient during those times of greatest awareness.
- Seizure-like movements with arms, chest or face in the last few minutes of death are a part of the body's shutdown process. These are not to be considered seizures or seizure activity.

- Unusual eye movement such as side to side.
- **Restlessness or confusion** is common. The patient may become increasingly confused about time, place and identity of close and familiar people. Reminders as to what day it is, what time it is and who is in the room will be comforting. Soft music and dim lights may be calming. Keep side rails up for safety.
- Visions of people and things you cannot see are common and not necessarily frightening, but comforting to the patient.
- **Incontinence**/decrease in the amount of urine/ darker urine color may become a problem. The nurse or hospice nursing assistant can help you obtain pads to place under the patient for more comfort and cleanliness.
- Moist-sounding breathing is caused by relaxed vocal cords and a small amount of oral secretions collecting in the back of the throat. The patient does not feel any discomfort from this and may not even be aware of it. Elevating the head of the bed or turning the patient on their side will usually quiet the breathing sounds.
- Hearing and vision may change. Keep some soft light on in the room. Assume that the person receiving care can hear, since hearing is thought to be the last of the senses to diminish. Explain to the patient what you are doing.

#### FINAL DAYS Continued from page 48

- **Cooler body temperature** may cause the arms and legs to become cool to the touch and bluish in color. You may notice that the underside of the body is much darker in color. These symptoms are a result of blood circulation slowing down and do not necessarily indicate that the person is too cold. Fevers are common as well.
- **Change in breathing patterns**, including 10to 30-second periods of no breathing (called apnea), may occur in the final stages of life.
- Unable to respond to touch or voice. Assume

that the sense of hearing remains and speak in a comforting voice.

• **Pain and discomfort** may diminish as death approaches, but continue to give medications as directed by the nurse.

Please let your hospice team know of any special or unique practice/ritual you would like to incorporate at this time. Community Hospice & Palliative Care will notify the funeral home at the time of death. Try not to be alone during this time. Include family and friends. Ask for assistance with caregiving needs. Use your hospice team for support.

#### Notes

#### Important Things to Attend to When Someone Dies

Often when death occurs, even expected death, the sadness can be overwhelming and interfere with the ability to take care of important matters that must be attended to in a timely manner. You may think, "Where do I begin?" and feel at a loss to start the process. Having a checklist may help you be more efficient and thorough. Although this list is not exhaustive, it highlights important tasks that need to be taken care of and when. Additional information can be found in the *Approaching Loss* booklet. Request a copy from your hospice care team if you do not have one.

#### **Documents You May Need:**

- 10–15 copies of the death certificate
- Social Security card
- Marriage certificate
- Birth certificate
- Insurance policies
- Deed and titles to property
- Stocks, bonds and/or IRAs
- Bank books
- Honorable discharge papers for veterans and/or VA claim number
- Automobile title and registration papers
- Loan and installment payment books and contracts

#### **Contact the Following:**

- Government agencies or benefits program, including alliances or unions that may be making payments to the deceased
- Creditors owed money by the decedent (credit cards, mortgage company, automobile loan agency)
- The deceased's bank and organize financial matters (roll over joint accounts; determine if deceased had a safe deposit box or a bank security box and follow appropriate procedures)

- Social Security Administration to determine if you are eligible for benefits
- Human Resources at the deceased's place of employment (if he/she was working) to discover whether there are monies you are entitled to such as vacation pay, death benefits, final wages, retirement plans, or other types of compensation.
- Your attorney to discuss estate matters. Do not pay any of the deceased's debts until after meeting with a lawyer

#### Request Change of Beneficiary or Name Forms from the Following:

- IRA
- Life insurance policies
- Pension plans
- 401(k) plans
- Utilities
- Stocks/bonds

Cancel or forward mail and newspaper delivery if necessary. Cancel automatic payments like annual memberships or subscriptions and on-line bill payments.

Make arrangements for final income tax return if appropriate and estate tax return as necessary.

#### Notes

# **GRIEF AND LOSS**

Grief is a normal, necessary, natural reaction to any loss. It is a roller coaster of emotions that involves physical, social, behavior, intellectual and spiritual responses. There is no right or wrong way to grieve. Each person grieves differently, in their own way and on their own timetable. During the course of caring for someone who is seriously ill, you may encounter feelings of grief known as "anticipatory grief." Even with anticipatory grief, however, there is no way to be fully prepared for the deep sadness you may feel after the death of a loved one.

The Bereavement Team will offer guidance and support as you adjust to changes in your life. A bereavement counselor will be available to you and your family. A variety of services, which include groups and individual support, will be offered to you at that time. Additional resources can be found at communityhospice.com.

#### **Helpful Hints to Promote Healing**

- Be kind to yourself
- Schedule a checkup with your family physician, if necessary
- Be sure to exercise and eat healthy food
- Check frequently that you have balance in your life: rest, play, meditation and work
- Reach out to others
- Tell and retell the story
- Don't fight the tears
- Find a creative outlet: music, art, journaling.
- Confront guilt and regret
- Be familiar with normal grief responses
- Be patient with yourself. Grief takes time
- Have realistic expectations of yourself

#### **Children Grieve Too**

Like adults, children will grieve in their own unique ways. However, they are often unable to identify, let alone manage these big feelings. Also, the grief may not manifest itself until months or years later. The grief of children can be intermittent and expressed in a variety of ways.

Speak to children in a language they can understand. Be aware of the child's developmental stage and use simple and honest words or phrases. You may need to ask children questions to get a better understanding of how they are feeling. Ask your hospice team for access to our bereavement counselors, who can help with this process.

There is wide variability in the understanding of death at a young age. By age 7, most children understand the key elements of death: that it is permanent and irreversible. Accepted developmental and grief responses of 3- to 5-yearold children include a lack of time/space concepts, belief that death is temporary and reversible, magical thinking, fear of abandonment and a need for physical comfort, reassurance and a stable routine.

As children mature, so does their understanding of death. The child may move from trying to understand death in a concrete way to a curiosity about the specifics of death and dying to reacting similarly to adults, but with fewer coping mechanisms.

As adults, answer all questions simply and honestly, reassure about the future, provide opportunities for feeling expression that include art and music and invite the child to be included in any funeral plans or rituals.

#### **Common Grief Reactions**

#### Shock

Shock and numbness is a typical grief reaction. You may feel as if you are on autopilot or just going through the motions. It takes the mind time to grasp that death has occurred.

#### Longing

You may feel a deep longing for your beloved. It takes time to accept the reality of the loss, and you may find yourself searching for your loved one. You might think you hear their voice or sense their presence.

#### **Sadness**

Not only will there be times you feel sad, you may experience waves of intense sadness. These waves are often unexpected and overwhelming and can bring tears.

#### Anger

Anger is one of the intense emotions that is a part of the normal grief reaction. Not everyone feels anger, but many do. You may be angry at the person who died, persons responsible, yourself, the situation or God.

#### **Guilt and Regrets**

When someone dies, we often second-guess ourselves. You may be wondering what would have happened if you had done or said things

#### Notes

differently. You may blame yourself for things you had no control over. Remind yourself you did the best you could at the time.

#### Relief

Some bereaved feel a sense of relief after the death. You may be relieved of your constant worries, your responsibilities of caregiving, or your loved one suffering. This is a normal part of the grief process.

#### Sleeplessness

Sleeplessness is common shortly after the death. You may have difficulty falling asleep or staying asleep or you may wake very early. Thoughts and deep feelings often surface at night.

#### **Changes in Appetite**

You may have an increased or decreased appetite.

## Forgetfulness and Inability to Concentrate

Many people experience confusion, memory loss and difficulty focusing on tasks at the beginning of their grief journey. It is helpful to write lists, make notes and keep to the familiar.

If you would like more information about our grief and bereavement services, please call 800.274.6614.

# PERSONAL PLANNING

#### **Advance Care Planning**

There is no easy way to plan for future health care decisions, but the best time to do it is when you are still in good health. During a health crisis, it may be too late, too difficult or just impossible to understand what your loved one wants. You and your loved one can prepare to make the choices that are right for you by developing advance directives in the form of a living will, health care surrogate and durable power of attorney for healthcare. These documents become active only when the person they cover is not able to make or communicate his or her own health care choices, unless otherwise directed. They can be changed at any time.

#### Honoring Choices® Florida Advance Care Plan

Honoring Choices<sup>®</sup> 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 would like a facilitator to meet with you, tell your nurse or your social worker—or contact us at HonoringChoicesFL.com.

#### **The Living Will**

Written or verbal instructions telling physicians and family members what life-sustaining treatment is acceptable if an individual becomes unable to make decisions and meets certain medical criteria.

#### **Durable Power of Attorney**

A document that allows a person to name an advocate to make healthcare decisions on his/her behalf and to manage many financial responsibilities.

#### **Healthcare Surrogate**

A document that allows a person to name an advocate to make healthcare decisions when

unable to communicate, unless otherwise noted. If a surrogate has not been selected by the individual, the healthcare provider will choose a decision maker based on Florida law.

#### Do Not Resuscitate Order (DNRO)

A Do Not Resuscitate Order (DNRO) is an instruction that you want to forgo cardiopulmonary resuscitation (CPR), if you have a medical emergency. The DNRO is a specific yellow form available from the Florida Department of Health (DoH). Community Hospice patients are not required to have a DNRO in place to receive hospice services.

Once 911 is called, emergency personnel are required to begin CPR upon arrival if you do not have a yellow State of Florida DNRO 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 24/7 Patient Priority Line first.** 

#### The Gift of Life: Organ and Tissue Donation

Organ and tissue donations are the gift of life. Through such donations, the lives of others can be prolonged, saved or improved. We realize that this is a difficult decision to make, especially at a time when you are experiencing intense grief, but many families have later said that their pain and loss was somewhat eased by having given a gift of life to another. Your loved one may have made their wishes known on their driver's license or voter registration card, or via the donor registry. You may receive a phone call after your loved one dies regarding honoring their wishes.

If you would like more information about organ and tissue donation, please ask a team member and arrangements will be made for further discussion.

#### **Memorial Planning**

## The Memorial Service: A Celebration of Life

A memorial service provides a sense of completion for both the deceased and the survivors. 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 the person's life; think about his or her values, special events, life's work, hobbies, travels, and contributions. It will help you cope with your grief.

In most cases, planning a memorial service falls to the immediate survivors. It is also common for the patient to participate in this planning. If the patient has reached an understanding and acceptance about their final moments on earth, planning a memorial service jointly can be very supportive to both of you.

#### **Things to Remember:**

- **Music** Music affects our feelings and the atmosphere in which we remember our loved one. Select hymns, songs, or other music that are your loved one's favorites, bring comfort or celebrate their life.
- **Readings** Reflective passages of sacred text, poems, and short stories are all helpful in remembering the person you are celebrating. Some faith traditions may require scripture be read, but many faiths are flexible and will include other types of readings as well.
- **Symbols of life** Use pictures, items from a person's hobbies, important moments in life, symbols of accomplishments or milestones achieved.
- Homily, eulogy, meditation Helps us integrate the music, readings and symbols with the loved one's life and indicates ways the departed inspired us.

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

#### Probate

The following explanation is information, not legal advice. Community Hospice urges you to consult an attorney for legal needs. There are two functions of probate court:

- 1. Once a person dies, probate court becomes involved to ensure the proper distribution of his/her assets. We advise you to consult with an attorney regarding this process. An attorney can answer any questions related to probating an estate.
- 2. While a person is alive, probate court may become involved if the patient is determined by a physician to be incompetent (medically unable to make decisions on their own due to confusion, etc.). This determination is then ruled on by the court in a lengthy proceeding. A lawyer needs to instruct the family on this process.

#### **VA Benefits**

There are specific burial benefits that the family may be entitled to if the patient is an honorably discharged veteran. It is recommended that all questions regarding entitlements be directed to the Department of Veterans Affairs. The patient's discharge papers will be needed.

United States Government Florida Department of Veterans Affairs 11351 Ulmerton Road, Suite 311-K Largo, FL 33788-1630 Benefits information and assistance: 800.827.1000

# PERSONAL PLANNING

#### **Personal Information and Records Checklist**

		LOCATION
□ Living Will	-	
Durable Power of Attorne	y for Healthcare	
General Durable Power of	Attorney	
	Name _	
	Address _	
	Phone _	
D Will		
	Attorney _	
	Executor of Will	
If you do not have a will, we enco and share it with family members	s and others named in the doc	ou do have a will, it is a good idea to review it at this time ument.
	Health insurance	
	Home insurance _	
	Auto insurance	
	Disability insurance	
	Renter's insurance	
Linsurance Agent/Broker	Name _	
	Address _	
	Phone _	
□ Real Estate Deeds	Location of property _	
	-	
	Titles in name of	

#### **Personal Information and Records Checklist**

		LOCATION
Mortgages, records or mortgage payments information	ation	
General Stocks, bonds, certificates of	f deposit	
Brokerage firm/broker		
	Name	
	Address	
	Phone	
Savings Account	Name	
	Account Number	
Checking Account	Name	
	Account Number	
□ Safe Deposit Box		
L	ocation of box and key	
	Name box is under	
	City, state, federal tax	
Returns for the past several	years	
Birth certificate		
Social Security card		
□ Marriage/divorce certificate	S	
Automobile titles		
When the person receiving care is n	o longer able to drive, a tra	nsfer of title and change in primary insured is recommended.
Military discharge papers		
Contracts (e.g., installment p	urchase agreements)	
Business records		
Receipts for furs, jewelry, etc.		
Credit cards		

#### **Memorial Worksheet**

Supporting our families in many stages of dealing with a serious illness is a vital part of our mission. One of the ways we are able to do this is to offer assistance in planning for the time ahead.

Having accurate memorial information available for newspapers and the funeral director is an important task, most of which can be done in advance. Hospice staff members are willing to help you in any way possible. This is best done prior to the death of your loved one, when there is time to think and talk, and gather complete information. The completed form can then be forwarded to the funeral director, who is responsible for placing obituary notices and making other arrangements.

We are honored to care for you and your family during this important time. Some families and friends choose to make tribute gifts or to direct gifts in lieu of flowers. Every donation is appreciated and meaningful to our families.

#### **Patient Information**

Name			
Address			
City	State	ZIP Code	
Birthplace			
Came to the area from		When	
Occupation			
Names of Spouse and Other Loved Ones			
Major/Area Employer No. of Yrs			
Church Religious Affiliation			
Organizations/Offices			
Major Achievements/Honors			
Military Service/Recognition			
Charity of Choice			

#### **Memorial Planning**

For many patients and families, pre-planning the funeral offers an amount of control and comfort. It provides an opportunity for all involved parties to share their ideas and choices at a less stressful time. Most funeral home directors welcome the opportunity to answer questions. Contact the funeral home of your choice to arrange a meeting. The funeral home director can also assist with an "Irrevocable Burial Contract." This is a preplanned and prepaid funeral. Along with peace of mind, preplanned funerals may also secure a lower price.

Also, the purchase of an "Irrevocable Burial Contract" is considered a legitimate way to spend down liquid assets if qualifying for Medicaid. Speak with the hospice social worker or chaplain if you need assistance with funeral planning.

If you have made funeral arrangements or wish to use the services of a specific funeral director, record that information here:

Funeral Home
Funeral Director
Address
Telephone
Cemetery Name and Plot Number
Specific instructions



## HOW TO SUPPORT COMMUNITY HOSPICE & PALLIATIVE CARE

As a nonprofit, community based organization, Community Hospice & Palliative Care relies on charitable support to fulfill its mission and vision of compassionate end-of-life care. Gifts to Community Hospice & Palliative Care enhance the quality of life for our patients and families, and support unfunded and underfunded patient care, outreach programs and services for those facing advanced illness or grief.

After a loss, many families are moved to create a memorial as a special way of remembering and honoring someone they loved. There are many ways to memorialize a loved one and support Community Hospice & Palliative Care.

- Make an honorary or memorial gift
- Request donations to Community Hospice & Palliative Care in lieu of flowers in obituaries
- Become a care companion
- Attend or sponsor an event
- Shop, donate or volunteer at the Community Hospice & Palliative Care Thrift Shops
- Establish an endowment fund in your loved one's memory
- Invest in planned giving opportunities
- Become an Honoring Choices<sup>®</sup> Facilitator

Your support enables Community Hospice & Palliative Care to continue to provide community programs and compassionate care to all who need them regardless of a person's ability to pay. For additional information, please call 904.886.3883 or visit **Connect.CommunityHospice.com**.

#### Notes

## **REFERENCE AND FORMS**

#### The Hospice Medicare Benefit and Other Insurance Coverage

Medicare provides a special program for those needing hospice care. The hospice benefit covers services, medications, supplies and equipment needed for the comfort of seriously ill patients.

All services, medications, supplies or equipment related to the seriously ill diagnosis must be pre-authorized by Community Hospice & Palliative Care. Medicare pays Community Hospice & Palliative Care directly at specified daily rates for care provided. Therefore, Community Hospice & Palliative Care delivers care based on the plan of care and is not responsible for care obtained for the patient outside of this plan of care.

Medicare Part D coverage will be assessed upon admission. Payment for medications not authorized under Part D are the patient's responsibility.

These restrictions apply only to the serious illness. Unrelated medical problems may be treated in the usual manner with your insurance coverage.

#### **Hospice Eligibility Explained**

- Patient has Medicare Part A
- Patient's doctor and the hospice medical director have confirmed the serious illness
- Patient signs a statement choosing hospice care benefits
- Patient receives care from a Medicareapproved hospice (Community Hospice & Palliative Care is Medicare-approved)
- Patient has months rather than years to live

#### The Hospice Benefit Periods Explained

The Medicare Hospice Benefit consists of two 90-day benefit periods followed by an indefinite number of 60-day periods. At the end of each period, the hospice care team must agree that the patient is seriously ill. If the patient is improving or if the illness has stabilized, the hospice care team will discuss alternatives to continuing hospice care with the patient and family. Medicare allows the patient to discontinue the Medicare Hospice Benefit before a benefit period is over. However, the days left in that period are lost. The next time the patient enters the Medicare Hospice Benefit, they will enter the next period.

If a patient has symptoms such as increased pain, acute nausea, vomiting or shortness of breath that are proving difficult to manage at home, a few days in a hospital or one of our inpatient centers for caring may be necessary. The need for this must be assessed by a hospice nurse. If such a trip out of home is needed, the hospice team members will help arrange transportation.

The Medicare Hospice Benefit requires the preauthorization of any hospital stay related to the serious illness, including the emergency room. Call the 24/7 Patient Priority Line day or night before making a trip to the hospital.

#### The Champus Program (TRICARE Insurance)

Because we are a Medicare-certified agency, we can be the provider of hospice services for those persons with Champus coverage, which has the same benefits as the Medicare program.

#### **Private Insurance**

Many, if not most, private insurance carriers have hospice coverage within their program. We will contact the insurance company regarding the coverage. Please contact your primary nurse or social worker with any changes to your healthcare coverage or if you have any questions.

#### **Financial Responsibilities**

I (we) understand that costs which are not approved by Community Hospice & Palliative Care and not in compliance with the agreed-upon plan of care may include the following:

- Deductibles and co-payments
- Care and treatment provided when no insurance coverage is available

#### FINANCIAL RESPONSIBILITIES Continued from page 60

- Care and treatment not related to the serious illness
- Room and board fees not covered by the third-party payer
- Residential or long-term care (level of care) room and board charges at a hospice inpatient care unit
- Any cost incurred for treatment with a physician and/or facility not contracted with Community Hospice & Palliative Care
- Medications not covered under Medicare Part D

#### Billing

### Q: Will there be a co-pay or deductible for hospice services?

A: Possibly, for some services, depending on the insurance coverage and the level of care your loved one receives. Medicare pays Community Hospice & Palliative Care directly for each day hospice is responsible for care. During hospice care, the patient should not receive a bill for services covered by Medicare. The current arrangement the patient has under Medicare Part B will continue to cover the doctor's costs. If any questions come up regarding billing, ask your hospice care team for help.

The patient or immediate family will be billed for any amount applied toward his/her personal deductible and/or co-pay after the partial payment has been received from the insurance company. Payment plans and options can be arranged in situations where payment would create a financial hardship for the patient or immediate family members.

A patient or family may also request a financial assessment to determine eligibility for payment plans and other financial options. A team social worker can provide more information and connect you to our financial services team.

#### Notes

#### Pursuant to 42 CFR §418.52 Patient and Family Guidelines — Rights and Responsibilities

#### The patient/family has the right to:

- To exercise his/her rights as a patient of the hospice 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.
- Be involved in developing his/her hospice plan of care.
- Make informed decisions regarding care or services.
- Accept or refuse care or treatment and be informed of potential results and/or risks.
- Formulate, at the individual's option, advance directives.
- Have complaints heard and reviewed.
- Confidentiality in accordance with state and federal regulations.
- Have his/her property and person treated with respect.
- Receive effective pain management and symptom control for conditions related to the hospice diagnosis.
- Choose his/her attending physician.
- Be free from mistreatment, neglect or verbal, mental, sexual and physical abuse, including injuries of unknown source.
- Receive information about the services covered under the hospice benefit.
- Receive information about the scope of services that the hospice will provide and specific limitations on those services.

#### The patient/family assumes the responsibility for:

- Providing daily physical and emotional support.
- Performing all agreed-upon procedures of care according to stated guidelines.
- Following the prescribed procedures for contacting Community Hospice & Palliative Care for assistance.
- Contacting Community Hospice & Palliative Care when admission to a hospital is pending.
- Informing Community Hospice & Palliative Care when unavailable for visits.
- Participating in and complying with the hospice plan of care.
- Helping your hospice care team assess your pain and working with them to develop an effective pain management and symptom control plan.
- Informing your hospice care team about any concerns, complaints or questions regarding needs and/or services being provided by Community Hospice & Palliative Care.

To report a complaint regarding your patient rights or the services you receive, please call Community Hospice & Palliative Care at 904-407-7097 or Agency for Health Care Administration at 888-419-3456.

To report abuse, neglect or exploitation, please call Community Hospice & Palliative Care at 904-407-7097 or Agency for Health Care Administration at 888-419-3456.

#### Notice of Patient Rights and Responsibilities

#### Pursuant to FS 381.026 Summary of the Florida Patient's Bill of Rights and Responsibilities

Florida law/FS 381.026 requires that a health care provider or health care facility recognize your rights while you are receiving medical care and that you respect the health care provider's or health care facility's right to expect certain behavior on the part of patients. You may request a copy of the full text of this law from your health care provider or health care facility. A summary of your rights and responsibilities are as follows:

#### RIGHTS:

- A patient has the right to be treated with courtesy and respect, with appreciation of his/her individual dignity and with protection of his/her need for privacy.
- A patient has the right to a prompt and reasonable response to questions and requests.
- A patient has the right to know who is providing medical services and who is responsible for his/ her care.
- A patient has the right to know what patient support services are available, including whether an interpreter is available if he or she does not speak English.
- A patient has the right to bring any person of his/her choosing while the patient is receiving treatment or is consulting with his/her health care provider, unless doing so would risk the safety or health of the patient, other patients or staff of the facility, or cannot be reasonably accommodated by the facility.
- A patient has the right to know what rules and regulations apply to his or her conduct.
- A patient has the right to be given by the health care provider information concerning diagnosis, planned course of treatment, alternatives, risks and prognosis.
- A patient has the right to refuse any treatment, except as otherwise provided by law.
- A patient has the right to be given, upon request, full information and necessary counseling on the availability of known financial resources for his or her care.
- A patient who is eligible for Medicare has the right to know, upon request and in advance of treatment, whether the health care provider or health care facility accepts the Medicare assignment rate.
- A patient has the right to receive, upon request, prior to treatment, a reasonable estimate of charges for medical care.
- A patient has the right to receive a copy of a reasonably clear and understandable, itemized bill and, upon request, to have the charges explained.
- A patient has the right to impartial access to medical treatment or accommodations, regardless of race, national origin, religion, handicap or source of payment.
- A patient has the right to treatment for any emergency medical condition that will deteriorate from failure to provide treatment.
- A patient has the right to know if medical treatment is for purposes of experimental research and to give his or her consent or refusal to participate in such experimental research.
- A patient has the right to express grievances regarding any violation of his or her rights, as stated in Florida law, through the grievance procedure of the health care provider or health care facility which served him or her and to the appropriate state licensing agency.

#### Notice of Patient Rights and Responsibilities

#### Pursuant to FS 381.026 Summary of the Florida Patient's Bill of Rights and Responsibilities

#### **RESPONSIBILITIES:**

- A patient is responsible for providing to the health care provider, to the best of his or her knowledge, accurate and complete information about present complaints, past illnesses, hospitalizations, medications and other matters relating to his or her health.
- A patient is responsible for reporting unexpected changes in his or her condition to the health care provider.
- A patient is responsible for reporting to the health care provider whether he or she comprehends a contemplated course of action and what is expected of him or her.
- A patient is responsible for following the treatment plan recommended by the health care provider.
- A patient is responsible for keeping appointments and, when he or she is unable to do so for any reason, for notifying the health care provider or health care facility.
- A patient is responsible for his or her actions if he or she refuses treatment or does not follow the health care provider's instructions.
- A patient is responsible for ensuring that the financial obligations of his or her health care are fulfilled as promptly as possible.
- A patient is responsible for following health care facility rules and regulations affecting patient care and conduct.

## If you currently have Medicaid or become Medicaid eligible, you have a responsibility to report suspected Medicaid fraud. Please call toll free 1-888-419-3456.

*Medicaid fraud* means an intentional deception or misrepresentation made by a person with the knowledge that the deception could result in some unauthorized benefit to him 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 Health Care Administration accepts complaints regarding suspected fraud and abuse in the Florida Medicaid system by phone at 1-888-419-3456 or on the Agency website at http://ahca.myflorida.com/Executive/Inspector\_General/medicaid.shtml.

#### Community Hospice & Palliative Care Notice of Privacy Practices

# THIS NOTICE DESCRIBES HOW MEDICAL INFORMATION ABOUT YOU MAY BE USED AND DISCLOSED AND HOW YOU CAN GET ACCESS TO THIS INFORMATION. PLEASE REVIEW THIS NOTICE CAREFULLY.

Community Hospice of Northeast Florida, Inc.<sup>®</sup> d/b/a Community Hospice & Palliative Care (Community Hospice & Palliative Care) 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 & Palliative Care and other health care providers, and personal and financial information which could be used to identify you.

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

#### How Community Hospice & Palliative Care Protects Your Health Information

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

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

Community Hospice & Palliative Care 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 & Palliative Care requires those contactors 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 & Palliative Care 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 & Palliative Care 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 & Palliative Care will retain your Health Information for 5 years after you are discharged from Community Hospice. Your Health Information, unless subject to a pending request from 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 5 years plus the number of years remaining until you reached 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 Florida Statute Section 400.611(3) before Community Hospice & Palliative Care will release your records.

The Community Hospice & Palliative Care medical record containing your Health Information is a single multidisciplinary record. Community Hospice & Palliative Care 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 & Palliative Care will respond to you or your designated 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 e-mail 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 & Palliative Care 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 & Palliative Care 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 & Palliative Care unless the request is one prohibited by law, or unless the circumstances would not allow Community Hospice & Palliative Care 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 & Palliative Care 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 & Palliative Care has violated your right to privacy under the terms of this Notice or under federal or state law. Community Hospice & Palliative Care 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 the 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 & Palliative Care ATTN: Privacy Officer/VP of Compliance and Quality/Chief Compliance Officer 4266 Sunbeam Road Jacksonville, FL 32257 904.407.7087

You may also 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 Ave., 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 allows Community Hospice & Palliative Care to use and disclose your Health Information without your prior authorization, in order to:

- 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 the aide can provide professional home health care in your home);
- **2.** conduct routine health care operations at Community Hospice & Palliative Care (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 & Palliative Care provides to you).

- 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 organ donation requests** (for example, if you are an organ donor, Community 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 & Palliative Care reserves the right to revise the terms of this Notice. If Community Hospice & Palliative Care materially changes the terms of this Notice, it will post a copy of the revised Notice on the Community Hospice & Palliative Care website at <u>http://communityhospice.com/</u>. The first use and effective date of this Notice is April 12, 2017.

#### NONDISCRIMINATION AND ACCESSIBILITY NOTICE AS REQUIRED BY ACA § 1557

Community Hospice of Northeast Florida, Inc.® d/b/a Community Hospice & Palliative Care (Community Hospice & Palliative Care) complies with applicable Federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability or sex. Community Hospice & Palliative Care does not exclude people or treat them differently because of race, color, national origin, age, disability or sex.

Community Hospice & Palliative Care provides free aids and services to people with disabilities to communicate effectively with us, such as:

- Qualified sign language interpreters
- Written information in other formats (large print, audio, accessible electronic formats, other formats)

Community Hospice & Palliative Care provides free language services to people whose primary language is not English, such as:

- Qualified sign language interpreters
- Written information in other formats (large print, audio, accessible electronic formats, other formats)

If you need these services, contact Kenny Stevenson, Civil Rights Coordinator.

If you believe that Community Hospice & Palliative Care has failed to provide these services or discriminated in another way on the basis of race, color, national origin, age, disability or sex, Kenny Stevenson, Civil Rights Coordinator, is available to help you. You can file a grievance with Kenny Stevenson, Civil Rights Coordinator, in person or in writing at 4266 Sunbeam Road, Jacksonville, FL 32257. You may also file a grievance via telephone at 904.407.5033, via facsimile at 904.407.7880, or via electronic mail to CivilRightsCoordinator@ CommunityHospice.com.

You can also file a civil rights complaint with the U.S. Department of Health and Human Services, Office for Civil Rights, electronically through the Office for Civil Rights Complaint Portal, available at https://ocrportal. hhs.gov/ocr/portal/lobby.jsf, or by mail or phone at U.S. Department of Health and Human Services, 200 Independence Ave., SW, Room 509F, HHH Building, Washington, DC 20201, 800-368-1019, 800-537-7697 (TDD)

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

#### HOW TO GET HELP WITH OTHER LANGUAGES

ATTENTION: If you need help or speak a non-English language, call 904.407.5033 to be connected with an interpreter at no cost.

ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame 904.407.5033.

ATANSYON: Si w pale Kreyòl Ayisyen, gen sèvis èd pou lang ki disponib gratis pou ou. Rele 904.407.5033.

CHÚ Ý: Nếu bạn nói Tiếng Việt, có các dịch vụ hỗ trợ ngôn ngữ miễn phí dành cho bạn. Gọi số 904.407.5033.

ATENÇÃO: Se fala português, encontram-se disponíveis serviços linguísticos, grátis. Ligue para 904.407.5033.

注意:如果您使用繁體中文,您可以免費獲得語言援助服務。 請致電 904.407.5033.

ATTENTION : Si vous parlez français, des services d'aide linguistique vous sont proposés gratuitement. Appelez le 904.407.5033.

PAUNAWA: Kung nagsasalita ka ng Tagalog, maaari kang gumamit ng mga serbisyo ng tulong sa wika nang walang bayad. Tumawag sa 904.407.5033.

ВНИМАНИЕ: Если вы говорите на русском языке, то вам доступны бесплатные услуги перевода. Звоните 904.407.5033.

> ملحوظة: إذا كنت تتحدث اذكر اللغة، فإن خدمات المساعدة اللغوية تتوافر لك بالمجان. اتصل برقم 904.407.5033.

ATTENZIONE: In caso la lingua parlata sia l'italiano, sono disponibili servizi di assistenza linguistica gratuiti. Chiamare il numero 904.407.5033.

ACHTUNG: Wenn Sie Deutsch sprechen, stehen Ihnen kostenlos sprachliche Hilfsdienstleistungen zur Verfügung. Rufnummer: 904.407.5033.

주의: 한국어를 사용하시는 경우, 언어 지원 서비스를 무료로 이용하실 수 있습니다. 904.407.5033.

UWAGA: Jeżeli mówisz po polsku, możesz skorzystać z bezpłatnej pomocy językowej. Zadzwoń pod numer 904.407.5033.

સુચના: જો તમે ગુજરાતી બોલતા હો, તો નિ:શુલ્ક ભાષા સહાય સેવાઓ તમારા માટે ઉપલબ્ધ છે. ફોન કરો 904.407.5033.

เรียน:

ถาคุณพดภาษาไทยคุณสามารถใชบรกิ ารชว<sup>่</sup> ยเหลือทางภา ษาได ฟรี โทร 904.407.5033.



### **HOSPICE ELECTION & ADMISSION CONSENT**

Other \_\_\_\_ □ Medicare Medicaid □ Private Insurance

A Community Hospice of Northeast Florida, Inc. d/b/a Community Hospice & Palliative Care (Community Hospice & Palliative Care) staff member has explained the Hospice Benefit to me. I have been given the opportunity to discuss the benefit, requirements and limitations of the hospice benefit.

- 1. I understand that hospice care is not curative. I understand that the focus of hospice care is to alleviate my pain and other symptoms associated with my terminal illness and related conditions.
- 2. I understand that by signing the election statement I am agreeing to waive my right to receive medical care and/or treatment related to my terminal illness and related conditions under my Hospice Benefit. I also understand:
  - a. My hospice care will be coordinated and managed by Community Hospice & Palliative Care medical and professional staff. Hospice services will be provided in accordance with my plan of care, which will be developed with me.
  - b. I am responsible for the cost of medical care and/or treatment for my terminal illness and related conditions not included in my plan of care and not authorized by Community Hospice & Palliative Care.
- 3. I understand that I may discontinue hospice care at any time by completing a revocation statement for Medicare and Medicaid and resume my full benefits under Medicare and/or Medicaid. I also understand that I may re-elect hospice care at any time when and if I am eligible.

I understand that I may discontinue hospice care at by requesting discharge for private insurance and resume my full benefits under my private insurance. I also understand that I may re-elect hospice care at any time when and if I am eligible.

I understand in the event I become Medicaid eligible while under the care of Community Hospice & Palliative Care, the effective date of the Medicaid eligibility will be the effective date for the hospice election.

4. I understand that I have the right to choose my attending physician.

My choice of attending physician is: \_\_\_\_\_

(Full Name and Credentials of the Physician / APRN / PA)

Effective Date of Hospice Election:

#### **Authorization for Services and Treatment**

I understand that hospice care is not curative and the goal of hospice care is to alleviate pain and other symptoms. The Community Hospice & Palliative Care program promotes the comfort and dignity of the patient and addresses the physical, emotional, social, psychological and spiritual needs of the patient and family.

I hereby give my permission for authorized personnel of Community Hospice & Palliative Care to perform all necessary procedures and treatments as prescribed by my physician(s) for the delivery of hospice care. I understand that the following hospice care and services may be provided to me during the course of my illness: physician, nursing, social work, therapy services, counseling services (spiritual and bereavement), hospice aide, care companion, durable medical equipment, pharmaceuticals, medical supplies, respite care, short term inpatient care and crisis intervention care. The extent of services and supplies are based on the patient's identified needs and determined by the hospice interdisciplinary team.

I understand that I have the right to participate in planning my care and treatment and that I may refuse treatment or terminate services at any time. 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 & Palliative Care nurse practitioner/APRN assigned to my care as the hospice attending, supervised by the Community Hospice & Palliative Care team physician.

• I do not wish to have a Community Hospice & Palliative Care nurse practitioner/APRN as my hospice attending.

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



# HOSPICE ELECTION & ADMISSION CONSENT

#### Insurance Benefit, Medicare, Medicaid

I certify that the information provided for Medicare, Medicaid or other insurance plan(s) hospice benefits is correct. I authorize direct payment of the hospice benefit from Medicare, Medicaid or other insurance plan(s) be made on my behalf to Community Hospice & Palliative. I authorize the release of all medical records as may be required by my insurance carrier to reimburse claims submitted on my behalf.

#### Photography/Videography

I understand that photography and/or videography is used by Community Hospice & Palliative 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.

#### Patient and Family Guidelines - Rights and Responsibilities - Nondiscrimination and Accessibility Notice

I have received the following: "Patient and Family Guidelines – Rights and Responsibilities" and the Nondiscrimination and Accessibility Notice.

#### Advance Care Planning

I have received information regarding creating advanced directives read it and/or had it explained to me. In addition, I understand that I am not required to have an Advance Directive or a Do Not Resuscitate Order in order to receive services from Community Hospice & Palliative Care.

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

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

I understand that Community Hospice & Palliative Care 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 health information and physical location. I hereby release Community Hospice & Palliative Care 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.

#### Authorization for Full Disclosure of Health Information for Treatment and Quality of Care

I voluntarily authorize, give my permission and allow use and disclosure (release) of all my heath information, including all records and other information regarding my health history, treatment, hospitalization(s), test and outpatient care. This information may relate to sensitive health conditions (if any), including but not limited to: drug, alcohol or substance abuse; psychological, psychiatric or other mental health impairment(s) or developmental disabilities (excludes "psychotherapy notes" as defined in HIPAA 45 CFR 164.501); sickle cell anemia; records that may indicate the presence of a communicable disease or noncommunicable disease; test for or records of HIV/AIDS; sexually transmitted diseases; genetic (inherited) diseases; copies of education assessments, test or evaluations, individualized educational programs; psychological and speech evaluations, immunizations recorded health information (such as height, weight), and information about injuries or treatment.

• I choose not to authorize the release of my health information to Community Hospice & Palliative Care. \_

Initials

Page 2 of 3 Form #5020, Revised 05/19 FL License # HPC5024096

Patient Name: \_

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



# HOSPICE ELECTION & ADMISSION CONSENT

I authorize the (release) of my information to Community Hospice & Palliative Care for the purpose of providing me with medical treatment and related services and products, and to evaluate and improve patient safety and the quality of medical care provided to all patients. I understand and agree that information created before or after the date of my signature below may be released upon request.

I authorize the use of a copy (including electronic copy) of this authorization for the release of the information described above.

I understand that health information received by Community Hospice & Palliative Care may be subject to lawful re-disclosure (rerelease), in accordance with applicable state and federal law, and in some cases, may no longer be protected by federal privacy law.

The authorization to release all of my health information will remain in effect until my discharge, death or the day I withdraw my permission.

I can revoke (withdraw) my permission at any time by giving written notice to the Community Hospice & Palliative Care Privacy Officer at the following address: Community Hospice & Palliative Care Privacy Officer, 4266 Sunbeam Road, Jacksonville, FL 32257.

I authorize the following individual to have access to review or request copies of my medical record generated by Community

	Individual's Name		Individual's	Relationship to Patient
nember(s), significant inswered to our satisfa	other(s), friends and I have		ask questions, and all	
atient Signature		1		Date
egal Representative S	ignature	Relationship to Patient	— 🔲 HC Proxy	Date
atient unable to sign t	for self, due to:			
ommunity Hospice ar	nd Palliative Care Represer	ntative Signature		Date
age 3 of 3 orm #5020, Revised 05/19	Patient Name:		Patient Number:	



#### FACILITY AGREEMENT

This document is an agreement between the facility, the patient/legal representative and the hospice regarding 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 he	ospice care under the following payr	nent status:	
		uipment, treatments and all hospi	ce services included in
	<ul> <li>Hospice Medicare: Hospice responsible for all diagnosis-related medications, equipment, treatments and all hospice services included in the plan of care and approved by the hospice.</li> <li>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.</li> <li>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.</li> <li>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.</li> <li>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</li></ul>		
		ons, equipment, treatments and a	ll hospice services
<ul> <li>below-named patient has elected to receive hospice care under the following payment status:</li> <li>Hospice Medicare: Hospice responsible for all diagnosis-related medications, equipment, treatments and all hospice services included in the plan of care and approved by the hospice.</li> <li>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.</li> <li>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.</li> <li>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.</li> <li>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.</li> <li>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.</li> </ul>			
Hospice Medicare/Medicaid & Skilled Medica	are Part A benefit simultaneously for	facility non-related condition of	
Facility Diagnosis: Hospice GIC: Facility will be reimbursed the one NOTE: The facility contracted pharmacy will bill			
The patient's <b>Room and Board</b> payment status (if	applicable) will be:		
Hospice (ICP) Medicaid: # Medicaid rate less any applicable client resp		ed to the facility by hospice at the	current facility
Hospice (ICP) Medicaid pending (hospice res Medicaid rate regardless of approval status.			at the current facility
Hospice (ICP) Medicaid pending prior to hos at the current facility Medicaid rate and may			o the facility by hospice
Payment for room and board through facility Private pay VA Diversion		it source):	
Change of patient's hospice status effective Discharge Revo		ve to:	
Print Facility Representative Name	Facility Representative Signa	ture	Date
Print Patient/Legal Representative Name	Patient/Legal Representative	Signature	Date
Print Hospice Representative Name	Hospice Representative Sign	ature	Date
Form #500IA, 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 ©2019 Community Hospice & Palliative Care, Community Hospice of Northeast Florida, Inc. & Licensed Since 1979

Form # 6002 FL License #HPC5024096



# 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	y is via telephone)	Date
Form #5072, Revised 07/15 FL License #HPC5024096 Original: Patient Chart Yellow: Proxy	Patient Name: Patient Number:	



# **DESIGNATION OF HEALTHCARE SURROGATE**

Should I ever become unable to make healthcare decisions for myself, it is my wish that the person named below serve as my healthcare surrogate to make healthcare decisions for me:

Surrogate Name:	
Address:	
City/State/ZIP:	
Telephone:	
In case of inability or unwillingness to act as my healthcare su healthcare surrogate:	ırrogate, I designate the following alternate
Alternate Surrogate Name:	
Address:	
City/State/ZIP:	
Telephone:	
<ul> <li>I understand that this designation will permit my surrogate to treatment for me, including life-sustaining medical therapy; to care; and to authorize my admission to or transfer from a heat a like a like</li></ul>	o apply for public benefits to help pay for the cost of my althcare facility. e of my preferences, and my designated surrogate has
Printed Name	Signature
Witness Statement: The declarant is personally known to me,	and I believe him/her to be of sound mind.
Witness	Witness Signature
A copy of this form should be given to your physician and the sur witness can be a spouse or blood relative.	rogate. The surrogate cannot sign as a witness. Only one
Distribution: Original - Patient Yellow - Chart Pink - Healthcare Surrogate	Form #4519 FL License #HPC5024096

Community Hospice & Palliative Care\*

# PAIN CONTROL DIARY

Name:
Patient

Patient #:

					L 32257 ice.com
10 WORST PAIN YOU CAN IMAGINE	Activity at the time of pain				4266 Sunbeam Road • Jacksonville, FL 32257 24/7 patient priority line 877.699.7300 • CommunityHospice.com
10 WORST PAIN )	How severe is the pain after one hour? (use scale above)				4266 Sunbe t priority line 877.699
7 8 9	Medication or non-drug method used to control the pain.				24/7 patien
3 4 5 6	Where is the pain?				-
1 2	How severe is the pain? (use scale above)				
Pain Scale: NO PAIN 0	Time				iin Control Diary
Pain Sc	Date				Form #K-Active Forms/Pain Control Diary FL License # HPC5024096 Revised 11/13

4266 Sunbeam Road • Jacksonville, FL 32257 24/7 patient priority line 877.699.7300 • CommunityHospice.com Activity at the time of pain 10 WORST PAIN YOU CAN IMAGINE PAIN CONTROL DIARY How severe is the pain after one hour? (use scale above) non-drug method used to control the pain. ര **Medication or** ∞ Patient #: ဖ Where is the pain? S 4 m 2 How severe is (use scale above) the pain? ~ Hospice & Palliative Care\* 0 Pain Scale: NO PAIN Time Form #K-Active Forms/Pain Control Diary FL License # HPC5024096 Revised 11/13 Patient Name: Date

Community Hospice & Palliative Care*	

# PATIENT INSTRUCTION SHEET

Patient Name: \_

\_ Patient #:

Date	Instructions	Purpose of Instructions	When to call the Patient Priority Line
Form #K-Active For FL License # HPC50. Revised 11/13	Form #K-Active Forms/Pain Instruction Sheet FL License # HPC5024096 Revised 11/13	24/7 patier	4266 Sunbeam Road • Jacksonville, FL 32257 24/7 patient priority line 877.699.7300 • CommunityHospice.com

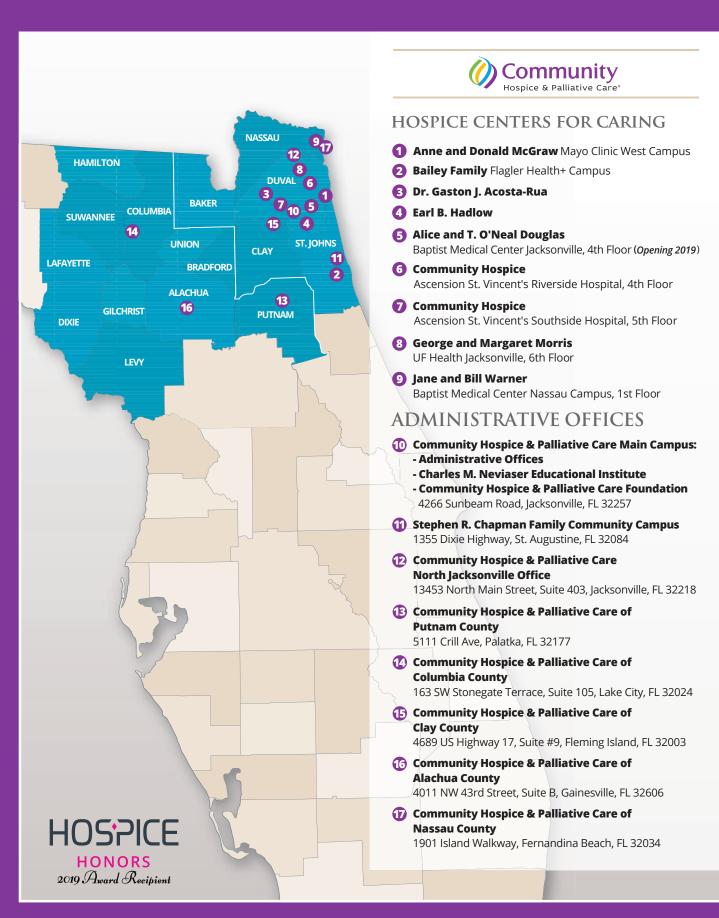
HOS HOS	Despice & Palliative Care®	PATIENT INSTRUCTION SHEET	CTION SHEET
Patient Name:	e:	Patient #:	
Date	Instructions	Purpose of Instructions	When to call the Patient Priority Line
Form #K-Active For FL License # HPC50 Revised 11/13	Form #K-Active Forms/Pain Instruction Sheet FL License # HPC5024096 Revised 11/13	24/7 patie	4266 Sunbeam Road • Jacksonville, FL 32257 24/7 patient priority line 877.699.7300 • CommunityHospice.com

$\mathbf{i}$	) Community Hospice & Palliative Care <sup>®</sup>	ity care®	Phy Phy	Patient Name: Physician Name:	ie i				All	Allergies:	
X	MEDICATION LOG	DO	Phi	Pharmacy Nan	Pharmacy Name – Related*: Unrelated:					*Indicates related medications provided by CHPC	provided
*	Day/Date										Order Date
	Medications	Time Due	Time Given	Time Given	Time Given	Time Given	Time Given	Time Given	Time Given	Comments	
	Bowel Movement										
rm #M	Form #Medication Log Revised 5/19							24/7 patie	42 nt priority lin	4266 Sunbeam Road • Jacksonville, FL 32257 24/7 patient priority line 877.699.7300 • CommunityHospice.com	ville, FL 32257 /Hospice.com

MEDICA * Day/Date Medic	MEDICATION LOG * Day/Date Medications Due										
Day	Date Medications	ÐO	Phố	armacy Nan	Pharmacy Name – Related*: Unrelated: _				+ In by ·	*Indicates related medications provided by CHPC	orovided
<b>2</b>	<b>Medications</b>										Order Date
		Time Due	Time Given	Time Given	Time Given	Time Given	Time Given	Time Given	Time Given	Comments	
Bow	Bowel Movement										
Form #Medication Log Revised 5/19	80 O							24/7 patie	42. nt priority lin	4266 Sunbeam Road • Jacksonville, FL 32257 24/7 patient priority line 877.699.7300 • CommunityHospice.com	ille, FL 322 Hospice.cc







**24/7 Patient Priority Line 877.699.7300 toll free • CommunityHospice.com** *Community Focused and Supported*