

**Deemed Status**

Accreditation by the Joint Commission recognizes the highest standard of excellence in safety and quality of healthcare.

*For patients receiving care in their home.*



HOSPICE  
OF MARION COUNTY  
*Feel better. Live better.*

*Patient/Caregiver Resource Guide*  
*September 2015 Edition*

## Quick Reference Numbers

A member of our hospice staff is available to discuss your questions anytime; 24 hours a day, 7 days a week, 365 days a year.

### Team:

<input type="checkbox"/> <b>East Team</b>	<b>(352) 873-7409</b>	<input type="checkbox"/> <b>West Team</b>	<b>(352) 237-6979</b>
East Toll Free	1-866-503-8882	West Toll Free	1-866-503-8883
<input type="checkbox"/> <b>ACT Team</b>	<b>(352) 291-5888</b>	<input type="checkbox"/> <b>Nursing Home Team</b>	<b>(352) 854-5255</b>
<b>(Assisted Living Facilities)</b>			
ACT Toll Free	1-866-613-5888	Nursing Home Toll Free	1-866-503-8884

### MONDAY – FRIDAY, 8:00 a.m. to 5:00 p.m.:

Ask for the team member with whom you wish to speak. If that person is unavailable, he or she will be contacted to return your call. In an emergency, ask to be connected with the supervisor.

### AFTER HOURS (ON-CALL SERVICE):

For questions, concerns or problems during the night or on weekends, our answering service answers your call. State your name, the patient's name, your phone number and the reason for your call. The on-call nurse will be notified and return your call. The on-call nurse has access to your electronic record and will answer questions and help you with any immediate concerns.

**If no response is received within 15 minutes, call (352) 402-6701.**

### Hospice House numbers:

Estelle's House	(352) 629-4556	Sylvia's House	(352) 629-1313
2897 SE 62nd Street		2895 SE 62nd Street	
Ocala, FL 34480		Ocala, FL 34480	
Legacy House	(352) 291-5100	Tuscany House	(352) 307-3417
9505 SW 110th Street		17395 SE 109th Terrace Road	
Ocala, FL 34481		Summerfield, FL 34491	

### Other Helpful Numbers:

Admissions Department (352) 873-7415 or 1-877-485-3396

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# Section 1 • Welcome



## *A Message from the CEO*

*Dear Patient and Family,*

*First, thank you for your confidence in choosing Hospice of Marion County. Second, please know we want to hear from you to ensure the excellence of our care. Give us your feedback right away, in person, by phone, and in the survey you will receive some months from now. Please take the time to fill out the survey as the quality of your experience is so important to us. It also helps us keep our standards high to provide excellent care to all for whom we provide care.*

*Excellence and customer service are the hallmarks of Hospice of Marion County and we continually strive to exceed your expectations. As your trusted guides, we hope the Patient/Family Resource and Guidebook will be a helpful at-your-fingertips reference. It is designed to instruct you on the best ways to care for your loved one. Any of the team members can go over the information with you whenever you wish. We are “on call” for you 24 hours a day, 7 days a week, and are never more than a phone call away.*

*Licensed by the State of Florida in 1983, Hospice of Marion County is also accredited by the national gold standard of care, The Joint Commission, whose seal is displayed below. Our designation was earned on the basis of quality of care, excellent service and safety.*

*We consider it a privilege to be here for you and those involved in your care. When the survey arrives, please do fill it out, call or write to us.*

*Respectfully,*

Mary Ellen Poe, RN, MSA, Chief Executive Officer



### **Deemed Status**

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# Statement of Patient Rights and Responsibilities

Florida law requires that your 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. All patients of Hospice of Marion County and their families have the following rights and responsibilities.

## The patient has the right to:

- Receive care in a safe setting
- Receive care of the highest quality
- Be treated with courtesy and respect, with appreciation of his or her individual dignity, and with protection of his or her need for privacy
- A prompt and reasonable response to questions and requests
- Know who is providing medical services and who is responsible for his or her care
- Know what patient support services are available, including whether an interpreter is available if he or she does not speak English
- Know what rules and regulations apply to his or her conduct
- Be given by the health care provider information concerning diagnosis, planned course of treatment, alternatives, risks, and prognosis
- Refuse any care or treatment, except as otherwise provided by law
- Be given, upon request, full information and necessary counseling on the availability of known financial resources for his or her care
- Know, if on Medicare, upon request and in advance of treatment, whether the health care provider or health care facility accepts the Medicare assignment rate
- Receive, upon request, prior to treatment, a reasonable estimate of charges for medical care
- Receive a copy of a reasonably clear and understandable, itemized bill and, upon request, to have the charges explained
- Have an advance directive, such as a living will or healthcare proxy; a patient who has an advance directive must provide a copy to the facility and his or her physician so that his or her wishes may be known
- Be free from mistreatment, neglect, or verbal, mental, sexual, and physical abuse, including injuries of unknown source, and misappropriation of patient property
- Receive information about the services covered under the hospice benefit
- Receive information about the scope of services that hospice will provide and specific limitations on those services
- Impartial access to medical treatment or accommodations, regardless of race, national origin, religion, handicap, or source of payment
- Treatment for any emergency medical condition that will deteriorate from failure to provide treatment
- 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
- Express grievances regarding any violation of his or her rights, as stated in Florida law, through the grievance procedure of Hospice of Marion County and to the Agency for Healthcare Administration

- Exercise his or her rights as a patient of the hospice
- Be told what to do in case of emergency
- Voice grievances regarding treatment or care that is (or fails to be) furnished and the lack of respect for property by anyone who is furnishing services on behalf of the hospice by calling (352) 873-7400 or 1-888-482-5018
- Not be subjected to discrimination or reprisal for exercising his or her rights
- Receive effective pain management and symptom control
- Participate in the planning of his or her hospice plan of care
- Have access to the plan of care
- Choose his or her attending physician
- Have a confidential clinical record. Access to or release of patient information and clinical records is permitted in accordance with 45 CFR parts 160 and 164
- Confidentiality with regard to information about his or her health, social and financial circumstances and about what takes place in the home or facility
- Be advised of the availability of the toll free Agency for Healthcare Administration Consumer hotline which is 1-800-419-3456

### **The patient has the responsibility to:**

- Indicate if they feel their privacy is being violated or their safety is being threatened
- Assure that the financial obligations of his or her health care are fulfilled as promptly as possible
- Provide 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
- Follow Hospice of Marion County rules and regulations affecting patient care and conduct
- Sign the required consents and releases that pertain to his or her care
- Report unexpected changes in his or her condition to Hospice of Marion County
- Provide a safe environment in which the patient's care is given either by the patient and/or caregiver
- Report to Hospice of Marion County whether he or she comprehends a contemplated course of action and what is expected of him or her
- Advise Hospice of Marion County of any dissatisfaction or problems with their care by calling (352) 873-7400 or 1-888-482-5018
- Follow the recommended treatment plan
- Treat Hospice of Marion County staff with respect and consideration
- Let Hospice of Marion County know when the principal advocate is leaving town and how to reach him or her if needed
- Keep appointments and to notify Hospice of Marion County staff when he or she is unable to do so for any reason
- Provide a patient's legal representative who has the responsibility to approve care, treatment and services when necessary
- Take responsibility for his or her actions if he or she refuses treatment or does not follow staff's instructions and/or plan of care
- Return resources loaned to them by Hospice of Marion County

# Section 2 • Communication with Team Members

## Using Our On-Call Services

Questions, concerns and problems often occur during the night or on weekends. We encourage you to use the on-call service when these needs arise. A nurse is always available through the on-call service.

When you call, please state your name, the patient's name, your phone number and the reason for your call. Please do not use your telephone while awaiting this return call! All calls are returned promptly. The on-call nurse has access to your electronic record and will answer questions and help you with any immediate concerns.

If your call is not returned in 15 minutes, please call (352) 402-6701.

**If there is a change in the patient's condition or a medical emergency, call Hospice of Marion County. We are always available to you – 24 hours a day, 7 days a week, 365 days a year.**

## Interpretive Services

In many situations, when there are communication barriers because people are not comfortable speaking or understanding the English language, a family member or friend may act as the translator between the patient and/or caregiver. The care team will identify if this is the most appropriate way to meet the care needs of the patient and family.

At times, the Hospice of Marion County staff speaks a second language and can communicate with those patients and/or caregivers.

Then there is the Cuidando con Carino, Compassionate Care Help Line for Spanish-speaking families. It is a toll-free phone line (1-877-658-8896) that offers information and resources for people living with or caring for someone with a serious illness.

Another way that Hospice of Marion County provides language interpretation services is through the language line. Every team member has access to a telephone number that puts an interpreter on the telephone to listen to what the staff member has to explain to the patient and/or caregiver and then tells them what was said in their native language. Then, the interpreter listens to what the patient and/or caregiver says and tells the team member what was said in English.

Remember, whenever there is any difficulty understanding what is being said, please do not hesitate to tell the Hospice of Marion County team member to find an interpreter.

# Section 3 • Hospice Services

## Hospice Services

Hospice of Marion County cares for patients with progressive illnesses with limited life expectancies, who choose comfort-oriented hospice care rather than aggressive curative treatments which may no longer be effective. Almost any situation can be managed in your private family home, an assisted living facility, a nursing home or a group home, or in other words, anywhere you call home. Occasionally the hospice team may recommend a higher level of care at one of our inpatient hospice houses. Inpatient care is a short-term solution to an acute symptom crisis. Many times, the crisis is resolved by interventions in the inpatient setting and the patient may return home or to the assisted living facility or nursing home.

## Team Members

**Physician:** Your personal physician or the hospice medical director will be responsible for the medical direction of your care.

**Hospice Nurse:** The registered nurse is responsible for the assessment and monitoring of pain and physical symptoms. The nurse also keeps the doctor updated on the patient's condition to maintain optimal comfort and symptom control. Licensed practical nurses also may make visits to assist with patient care.

**Chaplain:** Our hospice chaplain can help you explore spiritual concerns, can help you find a clergy person of your faith tradition or work with your own clergy, if desired.

**Volunteers:** Trained volunteers provide companionship for patients through reading, listening, giving emotional support, playing cards or games and writing letters.

**Social Worker:** Hospice social workers are experienced counselors who can help you talk about the changes that are happening, open up family communication and work with you to find the specific services you need. They can also help you sort out your advanced directives and other decisions that need to be made.

**Certified Nursing Assistant (CNA):** The CNA is available to provide bathing, hair care and other types of grooming or personal care services for the patient.

**Bereavement Facilitator:** When you are ready, bereavement staff is here to help you along your grief journey with ongoing individual guidance or in group support meetings. You will receive a letter within a month after your loved one's death to remind you that we are here for you. If you need assistance before then, please call us at: (352) 873-7456.

**Volunteers:** Specially trained individuals provide companionship and respite care for patients and their families. Respite volunteers stay with the patient while the caregiver runs errands, goes to appointments or takes a break. They make visits weekly or twice monthly for two-three hours at a time, but do not provide personal care or any medical services. Volunteers may read aloud, play cards or games, write letters, and write letters.

# Section 4 • The Hospice Benefit

## Hospice Benefits for Medicare, Medicaid, Insurance and Other Payment Methods

### Medicare Hospice Benefit

Medicare provides a special benefit program known as the Hospice Benefit for persons with advanced illness. Hospice services are delivered to patients wherever the patient resides. Hospice of Marion County is certified by Medicare to provide these services. This program covers staff visits, medications, supplies and equipment that are determined to be needed based on the life-limiting illness. There is no cost to the patient for care and services covered by the Hospice Benefit, however, daily room and board charges at our inpatient facilities are not covered by Medicare. Refer to Section 5 “Services in Inpatient Facilities” on page 13.

### Medicaid Hospice Benefit

Some patients may meet the financial eligibility requirements for reimbursement under Hospice Medicaid, which provides coverage as defined by the Medicaid benefit. Your Medicaid card will be used to confirm your eligibility for this benefit.

### Veterans Administration Benefit

Whether you use your Medicare benefit or the VA benefit, the care and services you receive are the same. Choosing to use Medicare does not change your eligibility for VA services in any way.

### Private Insurance Benefit

Most private insurances have a hospice benefit. A member of your hospice team will discuss how insurance benefits are accessed. Some benefit plans have out-of-pocket deductibles and co-pays that are the patient’s responsibility. Pre-authorization and continued authorization from the insurance company for the patient’s level of care may be required.

### Private Pay

Hospice services provided that are not covered by Medicare, Medicaid or private insurance reimbursement will be the responsibility of the patient. A member of the hospice team will meet with you and discuss any assessed fees prior to admission and as changes in your plan of care may occur. A sliding fee scale will be used to assess your ability to contribute to the non-reimbursed costs. Hospice of Marion County provides care and services regardless of a person’s ability to pay.

### *Be assured that:*

- Medicare/Medicaid patients will have no co-payment and no deductibles with hospice.
- Family bereavement support will continue for 13 months after the death, if desired.

## How Hospice Benefits Work

All patients are admitted to hospice services with a primary diagnosis of a life-limiting illness. Hospice is responsible for providing required services related to the hospice diagnosis and those included in the patient’s Plan of Care. For Hospice of Marion County to pay for care and services, the request for additional care or services must be discussed with your assigned hospice nurse or social worker. ***If you elect to receive medical care or hospital services which are not directly provided or authorized by Hospice of Marion County,***

***you may either self pay for that service or withdraw from the Hospice Benefit.*** Medicare and Medicaid pay Hospice of Marion County directly at specified daily rates for the care provided. Remember, these restrictions apply only to the terminal or advanced illness diagnosis. Unrelated medical problems will be treated through your regular healthcare provider.

**The Medicare Hospice Benefit also has established benefit periods:**

- Two 90-day benefit periods, followed by an unlimited number of 60-day benefit periods
- After the second 90-day benefit period, a physician will make a visit to determine if hospice care is still appropriate

**What is not covered in hospice services?**

When you choose hospice care, Medicare or Medicaid will **not** pay for the following:

- Treatment intended to cure your illness.
- Prescription drugs that are not related to the life limiting diagnosis.
- Care from any provider that wasn't set up by your hospice team.
- Room and board charges in nursing homes, assisted living facilities or hospice houses.
- Care in an emergency room unless it is arranged by your hospice team.
- Care in an inpatient facility unless it is arranged by your hospice team.
- Ambulance transportation unless it is arranged by your hospice team.

**Does the Hospice Benefit cover hospital visits?**

We prefer to provide symptom management in the patient's home or at one of our four hospice houses. We also contract with Munroe Regional Medical Center, Ocala Regional Medical Center and West Marion Community Hospital to provide this service, if necessary. However, the Medicare Hospice Benefit requires the pre-authorization of any hospital stay related to the advanced illness, including a visit to the emergency room.

**Note: it is important that you call Hospice of Marion County day or night if you are considering any type of hospital visit!**

## Levels of Care

Medicare, Medicaid and many insurance companies use the term "Level of Care" to refer to the intensity or setting a patient needs at any given time. ***Each level of care must be justified*** by Hospice of Marion County for the insurance payer to reimburse hospice for that care. It is not unusual for patients to move from one level of care to another during their stay in hospice.

**Routine Home Care**

Most patients can be cared for in their own home by their own caregiver. Members of the hospice team make regular visits to assist the family or caregivers to care for you.

**General Inpatient Care**

Short-term care provided in a contracted local hospital or hospice house. Through direct physician oversight and regular Hospice of Marion County staff involvement, issues of acute pain or symptom management are addressed and treated.

**Respite**

Patients can stay in a nursing home with which Hospice of Marion County has a contract or a hospice house,

if a bed is available, for up to five days for respite care when primary caregivers need time off from care giving. The payment per day from Medicare or Medicaid goes directly to the nursing home.

### **Continuous Care (also called Crisis Care)**

Crisis care staff provide a high level of onsite care to avert the need for hospitalization.

## **Services in Long Term Facilities**

At Hospice of Marion County, we consider wherever a patient lives as his or her home. This includes people who live in an Assisted Living Facility (ALF) or a nursing home. People living in facilities may receive hospice care. A team of specialized hospice workers, who are familiar with the staff of these facilities, provide support and care for the patient. Hospice of Marion County works collaboratively with all the facilities in our service area.

# **Section 5 • Services in Inpatient Facilities**

## **Services in Inpatient Facilities**

Sometimes pain and symptoms need skilled attention around the clock. In those instances, general inpatient care in a facility may be arranged when necessary. The following are examples for which this acute level of care may be necessary:

- Pain and/or symptoms that need to be managed in a way that cannot be accomplished at home or the patient's place of residence.
- Learning is needed on the complex care/medication delivery that the patient requires.
- Complex wound care that cannot be accomplished at home or in patient's place of residence.

### **How is this paid for?**

Medicare and Medicaid, as well as some commercial insurers, approve an inpatient admission for a hospice patient when there is medical appropriateness. The physician and nurse oversee the need for this level of care.

When the medically necessary symptoms are under control and/or when the care can be safely and therapeutically provided in another setting, the insurer will require that hospice no longer bill them for inpatient care. The patient's status must be changed from inpatient to routine status at this time and room and board charges in our hospice house facility will apply for each day on routine status. The charge for room and board is not covered under the Medicare or Medicaid Hospice benefit.

### **When a patient is in the hospice house receiving routine care, who is responsible to pay for the room and board costs?**

The patient is responsible for these charges. If finances are a problem, a financial assessment can be done and a sliding fee scale will be used to determine the adjusted amount. When the hospice team has determined that the patient's condition no longer requires care in a hospice house, the hospice team will assist the family in seeking an alternative setting for the patient.

# Section 6 • Safety Information

## Emergency Management Information

Hospice of Marion County has developed guidelines to assist our patients and families in emergency preparedness in the event of a disaster such as a hurricane, tornado, fire or flood.

Patients and families can cope with disaster by preparing in advance and working together with your hospice team. Always call Hospice of Marion County in the event of an emergency and be assured that your hospice team will work with you to ensure your needs are met. You may also call Marion County Emergency Management at (352) 369-8100.

The following are key areas to focus on for safe patient care.

## Safety

### Preventing Falls:

- Remove electrical cords from walkways.
- Wear non-slip footwear.
- Secure or remove area rugs.
- Install grab bars near toilet and shower/bath tub.
- Have walkways and stairs well-lighted and clear of objects. Use nightlights.
- Use bath mats or non-slip stickers in bath tub and shower.
- Place the shower chair on a flat and level surface.
- Be aware of side effects from medications.
- Always lock wheelchairs when getting in or out of them.
- Rise slowly from sitting or lying down to prevent dizziness.
- Make sure robes, gowns or other clothing do not drag on the ground.
- Use a baby monitor, chair or bed alarm to monitor the patient.
- Provide good lighting by using night lights or keeping lights on at night.
- See section "Moving the Patient" for correct moving techniques.

### Home Oxygen and Fire Safety:

- Make sure "NO SMOKING, OXYGEN IN USE" signs are posted.
- Do NOT smoke while using oxygen because it is highly flammable and will catch on fire.
- If using oxygen, enforce NO SMOKING rule for the patient as well as all visitors.
- Keep oxygen at least six feet away from an open flame or heat sources such as gas stoves, barbecue grills, space heaters, candles and fireplace.
- Do not use any oils or petroleum-based products when using oxygen. If oxygen is mixed with petroleum-based products, it may cause a fire! Example of a petroleum-based product is Vaseline. Water-based products, such as KY Jelly, are fine.
- Keep portable heaters at least three feet from objects.
- Do Not overload electrical outlets.
- Use only proper size fuses and light bulbs.
- Consider having a working fire extinguisher in the home.
- Have an escape plan and outside meeting place in case of fire.

- Use ashtrays and do not leave cigarettes unattended.
- Do not smoke in bed.
- Oxygen concentrator should not be placed in an enclosed place. Keep at least 12 inches from any wall or combustible material (such as curtains, clothing, newspapers, tissues, etc.).
- Always keep your concentrator plugged into a company approved outlet or one that has a properly checked ground. Do not use an extension cord.
- Replace frayed electrical cords.
- Do not leave a heating pad on for more than thirty minutes or fall asleep with it on.
- Install smoke detectors. Check batteries monthly and replace them every six months.

**Call your primary nurse or hospice for any equipment problems or whenever an accident/fall occurs!**

## Infection Control in the Home

Hospice of Marion County is committed to helping our patients and families maintain a safe environment and prevent the spread of infection by providing information and instruction regarding infection control techniques.

- Hands, including between the fingers, should be thoroughly washed with soap and water before and after any care provided to your loved one. Wash for at least 15 seconds, rinse well and dry completely. Hands should also be washed before and after handling medications, before preparing or eating food, after removing gloves, and if they become contaminated with body fluids. If a sink has many users, keep a roll of paper towels nearby for use instead of a cloth towel.
- Don't forget to wash your loved one's hands.
- Disposable gloves are to be worn whenever there might be direct contact with body fluids (blood, urine, pus, stool, saliva, and drainage of any kind).
- A moisture-resistant gown or apron should be worn whenever it might be possible to soil clothing through contact with a body substance.
- A mask and protective eyewear should be worn whenever it might be possible for a body substance to splash into the mouth, nose, or eyes.
- Remember to cover the nose and mouth with a tissue when coughing or sneezing. Dispose of tissues in a container or bag that closes. Wash hands after sneezing, coughing or blowing your nose.

## Biomedical Waste

**“Biomedical Waste”** (also called “infectious waste”) is defined as “any solid or liquid waste that may present a threat to others”. **Blood and body fluids** are classified as “Biomedical Waste” because they have the potential to harbor disease-causing organisms such as human immunodeficiency virus (HIV) and Hepatitis. **HIV and Hepatitis B and C** can be spread when infected fluids enter the body through:

- Needle stick injuries
- Splashes into the mouth, nose, or eyes
- Cuts, scrapes, rashes, and other breaks in the skin
- Sex (oral, vaginal, anal)

Other items or materials that are considered to be **Biomedical Waste** include:

- Used, absorbent bandages or dressings saturated with blood or body fluids that have the potential to drip or splash.
- Devices that retain visible blood, such as intravenous (IV) tubing, syringes, or catheters.
- Sharps or devices capable of puncturing, cutting, or penetrating the skin. These include needles, lancets, intact or broken glass contaminated with blood or body fluids, and intact or broken hard plastic contaminated with blood or body fluids. Used needles must never be “recapped or broken”. They should be placed in the sharps container immediately after use. Needles are never to be “reused”. Broken glass or plastic that may be contaminated with blood or body fluids should not be picked up directly with hands, but cleaned up with a brush or broom and a dustpan, or tongs and placed in rigid container.

Other items or materials that are considered to be **Non-Biomedical Waste** include:

- Urine, stool, sputum, sweat, tears, saliva or vomitus are not considered to be biomedical waste unless they contain visible blood.
- Items that have a small amount of blood or other body fluids are not considered biomedical waste and should be placed in a regular, leak proof plastic bag for regular trash disposal. Double bagging further prevents any leakage.

## Instructions for Handling Biomedical Waste

If the waste is **saturated** with blood or with body fluid that contains visible blood, place in a red plastic bag provided by Hospice. *Examples of biomedical waste: a dressing full of blood or an incontinent product with bloody urine.*

- Do not overfill the bag. Securely close when  $\frac{1}{4}$  -  $\frac{1}{2}$  full then start another bag.
- Do not remove contaminated items from the bag.
- Do not place any other trash in the bag except waste saturated with blood or body fluid that contains visible blood.
- All other medical waste (e.g., soiled incontinent supplies, dressings without blood) should be double bagged in plain plastic bags and placed in your regular household garbage.
- Do not place red bags in your regular household garbage. They will be removed by the nurse at each visit.

**If you have a sharps container:**

- Do not overfill the box. Close it securely when it reaches the designated fill-line (approximately  $\frac{3}{4}$  full).
- Do not place the sharps container in the regular household garbage. It will be removed by the nurse as appropriate.
- Do not put anything but used sharps in the sharps container.
- Do not remove any items from the sharps container.

**Important Facts to Remember:**

- Biomedical Waste must never be placed where a child or animal can get into it.
- Biomedical Waste should never be placed outside the home, on a porch or patio where its contents may become exposed.
- All sharps go into a sharps container.
- Biomedical Waste should never be placed in the sharps container.

- To decontaminate or disinfect hard, non-porous surfaces contaminated with blood or body fluids: Wear disposable gloves and use paper towels or newspaper to absorb the fluid. Clean the area thoroughly with soap and water then wet the area thoroughly with a mixture of one (1) part bleach and ten (10) parts cold water leaving it on the surface for a minimum of 10 minutes. Bleach solution should be rinsed off metal to prevent corrosion.
- Your hospice nurse will be happy to answer any questions or to explain these recommendations in more detail.

## **Management and Disposal of Controlled Medication in the Patient's Home**

*(Below is a summary of the official policy that follows.)*

Hospice of Marion County, Inc. complies with federal and state regulations for management and disposal of controlled medication in the patient's home. Controlled substances in the patient's home are handled according to the most recent laws (Controlled Drug Act of 1970).

Controlled medication in the patient's home must be disposed of appropriately when they are no longer needed by the patient, at the time of death or upon completion of infusion therapy. The nurse will dispose of medications in the presence of a witness (preferably a non-hospice employee) as follows:

1. In situations where diversion or over use is suspected, a plan will be developed by the Interdisciplinary Team (IDT) to change the type of medication, the amount of medication, the route of medication, or the packaging to minimize or prevent those occurrences.
2. The controlled medication is identified by checking the medication label to verify the patient's name and medication prior to disposal.
3. A medication count for medications to be destroyed including those in the hospice kits is performed and the total number is documented.
4. Medication(s) are not disposed by flushing them down the toilet or drain.  
Note: The Florida Department of Environmental Protection states that flushing medications down the toilet or drain can cause contamination to Florida's aquatic environment because the wastewater treatment systems are not designed to remove many of the medications.
5. All hospice purchased prescription medications shall be disposed of by mixing with water and kitty litter in a plastic bag or placed in liquid drug buster and placed in the trash at the time of death of the patient with consent of the family or caregiver. In some situations, while the patient is still on service, disposal may be warranted by the hospice plan of care and/or recommendations of the primary physician and/or HMC Medical Director.
6. Medication patches are folded and cut in half so that the adhesive side adheres to itself and disposed in the trash or in the liquid drug buster.
7. Refusal by family members to dispose of controlled drugs is documented. A reason for refusal is requested and documented. Suspicions of improper use of medications are reported.
8. Hospice staff should not take any medications from a patient's home.

# Controlled Drugs in The Home Policy

## I. Policy Purpose:

To ensure that medications are safely and accurately managed in the patient's home.  
To ensure proper disposal of all controlled medications.

## II. Policy Definitions:

Hospice of Marion County, Inc. will comply with federal and state regulations governing the procurement, dispensing and disposal of controlled drugs in the patient's home. Handling of controlled substances for home care patients will be performed according to requirements outlined in the Federal Comprehensive Drug Abuse Prevention and Control Act of 1970, commonly known as the Controlled Drug Act. Adequate records, control and accountability of dispensed controlled drugs will be maintained.

## III. Policy Procedure:

- A. The Controlled Drug Act created the following five (5) drug schedules based on the potential for abuse:
- a. Schedule I contains drugs with high potential for abuse and no accepted medical purpose, for example, heroin, marijuana.
  - b. Schedule II contains drugs with high abuse potential such as morphine meperidine, methadone, hydromorphone, fentanyl, cocaine, amphetamines, codeine, methylphenidate, and secobarbital.
  - c. Schedule III contains drugs with a potential for abuse lower than Schedule II, such as Tylenol with Codeine, dronabinol (marinol), and anabolic steroids.
  - d. Schedule IV contains drugs with lower potential for abuse than Schedule III and includes meprobamate, chloral hydrate, lorazepam, diazepam, chlordiazepoxide, and depo-testosterone.
  - e. Schedule V contains drugs with a low potential for abuse relative to Schedule IV, such as the Codeine containing cough syrups and Lomotil.
- B. Controlled drugs in schedule II through V are subject to special handling, storage, disposal and recordkeeping. The following responsibilities have been delegated to ensure specific requirements are met:
- a. Licensed Nursing Personnel implement procedures for monitoring and disposal of controlled drugs as stated in policy IDT 0202 Medication Management Administration and Disposal of Drugs.
  - b. Medication management of these drugs is under the direction of the primary physician or the hospice medical director and the team Clinical Coordinator.
  - c. The licensed nurse is responsible for the education of the patient and/or family regarding the disposal of the medications and documentation of the same.
  - d. All hospice provided controlled medications shall be disposed of by mixing with water and kitty litter in a plastic bag or placed in liquid Drug Buster disposal system and placed in the trash at the time of death of the patient with the consent of the family or when these medications are no longer needed by the patient.
  - e. Controlled medication patches are folded and cut in half so that the adhesive side adheres to itself and disposed in the trash or in the liquid Drug Buster.
  - f. The authorized paper Medication Disposal form H0007 will be utilized to obtain necessary signature and disposal of controlled medications checked off on the computer/paper Discharge Summary form H0008.
  - g. The procedure to follow if a patient caregiver refuses to dispose of controlled medications is as follows:
    - i. Document the name and quantity of each controlled medication that will remain in the possession of the family.
    - ii. Document the name and the relationship to the patient of the person that will retain ongoing responsibility of the medication.
    - iii. Obtain that person's signature on the Medication Disposal form acknowledging that he/she has been educated about the risk of retaining this medication.
  - h. The Pharmacy and Therapeutics Committee approves all policies and procedure related to controlled medications.
- C. In situations where diversion or overuse is suspected, a plan will be developed by the Interdisciplinary Team (IDT) to change the type of medication, the amount of medication, the route of administration, or the packaging, to minimize or prevent these occurrences.

# Section 7 • Care Guide

## Caring for the Patient

### Pain Management

Pain and discomfort are common symptoms with cancer and other end-stage diseases. Even if the person is in a deep sleep or coma, pain may be felt. Grimacing or moaning when turned and positioned are cues that pain medicine may be needed. One sign that pain is well managed is when the person can tolerate turning from side to side, as well as the back, without cues of discomfort. Be aware of what long-acting medication is being used to prevent pain. It's also important that an immediate-acting medication is available for sudden bursts of pain. Frequent adjustments of doses and routes of medications are usually necessary as the disease progresses.

#### **There are many types of Pain and Pain Medicines**

For mild to moderate pain: over-the-counter medications or prescription medicine may be ordered. For moderate to severe pain: the nurse will obtain orders from the doctor for medication.

There are times when more than one type of medicine may be needed to treat the pain. It is important to describe your pain the best way you can to help the nurse identify the type of pain. For example, nerve pain may be described as tingling or burning. Pain caused by swelling may be described as pressure.

The nurse will also ask you to rate your pain, using a pain scale that is best suited for you. This allows your hospice team to help you stay as comfortable as possible by making changes to your medication, based on your pain level.

#### **How Pain Medication is Taken:**

Most pain medication is taken by mouth. If you have difficulty swallowing and cannot take a tablet or liquid, the doctor may order other routes. These may include:

- Suppositories
- Concentrated liquids under the tongue
- Infusion pumps (These are sometimes used if pain is difficult to manage. This option would be thoroughly discussed with you by your nurse or doctor.)

Some medications are long-acting, which means they are taken regularly and work around the clock. There are times when pain comes about in spite of a long-acting pain medicine. The nurse may refer to this as "breakthrough" pain. All patients taking a long-acting pain medication also need to have a short-acting pain medication available to take in case of breakthrough pain.

#### **Possible Side Effects of Pain Medication**

All medications have some kind of side effects, but not all people experience them. Some of the most common side effects are:

- Nausea and vomiting
- Drowsiness
- Constipation (all patients taking narcotic pain medication need to be on a laxative and stool softener routinely to prevent constipation)

It is important to inform your nurse if you experience any of these side effects. Additional medication may be needed to control side effects, and often times the side effects subside after 24-48 hours.

## When to Take Your Pain Medication

To help your pain medicine work best:

- Take your medicine regularly, as ordered. Taking medicine regularly will help keep pain under control. Never skip a dose, never wait for the pain to get worse before taking your medicine.
- Once you feel the pain, it is harder to get it under control.
- If certain activities make your pain worse, you may need an extra dose of break-through pain medicine before doing them. Always check with the nurse so that you are taking your medication as ordered.

The goal is to PREVENT the pain. If the medication or treatment does not work, changes can be made. It is important to keep a record of medication you have taken. Your nurse will review the record and make adjustments if necessary.

Will the patient become addicted?

No! The patient has an illness that causes pain. Taking a pill to stop this physical pain is the treatment, not a bad habit. Studies show that pain medicine used this way will rarely cause addiction. It is important that each patient be supported with the right kind and amount of pain medicine.

## Non-Drug Treatment of Pain

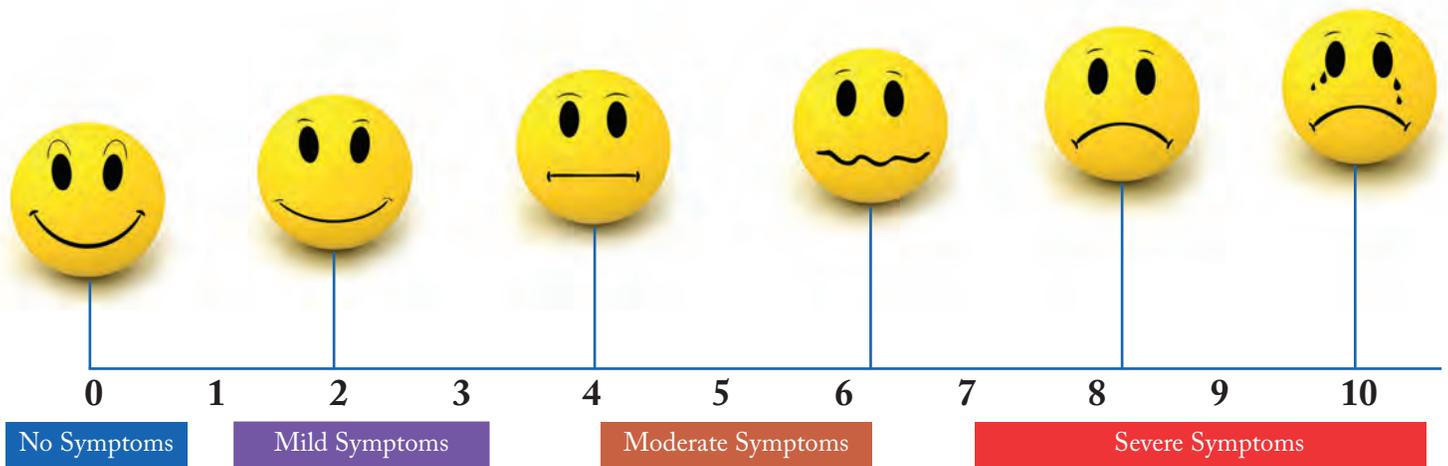
Non-Drug treatment of pain includes breathing, relaxation, Reiki, hot/cold packs, aroma therapy, music, imagery, distraction and rest.

## Why Pain Should be Controlled

Pain can keep you from being active, from sleeping well, from eating and from enjoying your family and friends. Pain can also make you feel anxious or depressed. All pain can and should be controlled in order to achieve a maximum quality of life.

**Please talk to your Hospice of Marion County team about your pain.**

**We are committed to keeping you comfortable.**



## **Morphine Liquid Concentrate (also known as Roxanol)**

Morphine liquid concentrate is used for immediate effects of pain control or shortness of breath. It is usually given when a patient is having a hard time swallowing pills, or when a patient is having difficulty breathing or severe shortness of breath. Morphine liquid concentrate is absorbed by the mucus membrane in the mouth, and the larger blood vessels under the tongue. It does not need to be swallowed in order to be effective. It also provides the same pain control as other forms of morphine, although it is immediate release.

### **Helpful Hints:**

- Be sure you have been instructed on giving the medication properly. The doses are usually 0.25 ml – 1.0 ml, depending on how your doctor has ordered it. The pharmacy will send a dropper or syringe for accurate dosing.
- Roxanol, as other pain medications, may cause constipation. Be sure to let your nurse know if the patient has not had a bowel movement for 2 or more days.
- The medication will take 20-40 minutes to absorb and be effective. You may need to be patient until it takes effect. Your nurse will let you know how soon another dose can be given.
- You may give it even if the patient is unable to swallow. Place the medication under the tongue, between the lip and gum, or in the inner cheek area.
- As with other morphine products, nausea and/or vomiting may occur, although this possible side effect usually will last only 1-2 days. If this occurs, be sure to let your nurse be aware. If it continues for longer than 2 days, you may need to give an anti-nausea medicine 30-45 minutes before giving a dose. Your nurse will keep you informed of how to best dose the medications.
- Be sure the head of the bed is raised when giving morphine liquid concentrate under the tongue. If swallowing is an issue, the medication may cause choking if the head is not raised when attempting to give it.
- It also may cause sleepiness, although this effect usually will pass within the first 24 hours or so.

## **Methadone Tablets or Liquid Concentrate**

Methadone Liquid Concentrate and Methadone Tablets are used for long acting pain control and continuous relief of pain symptoms.

### **Helpful Hints:**

- Methadone tablets can be broken, crushed, mixed in water or juice, or inserted rectally.
- Methadone is quickly absorbed into the blood stream, however as a long-acting medication, it may take 12 to 24 hours to reach maximum analgesic effect.

### **Dosing:**

- You may give Methadone Liquid Concentrate and Methadone Tablets even if the patient is unable to swallow. Place the medication under the tongue, between the lip and gum, or in the inner cheek area.
- Be sure the head of the bed is raised when giving methadone liquid concentrate under the tongue. If swallowing is an issue, the medication may cause choking if the head is not raised when attempting to give it.
- As with other opioid narcotics, nausea and/or vomiting may occur, although this is a side effect, and usually will last only a couple of days. If nausea occurs, be sure to let your nurse be aware. If it continues for longer than 2 days, you may need to give an anti-nausea medicine an hour before giving a dose of methadone. Your nurse will keep you informed of how to best dose the medications.
- Methadone, as with other opioid pain medications, may cause constipation. Be sure to let the nurse know if the patient has not had a bowel movement for 2 or more days.

- Methadone may cause drowsiness or confusion, although this side effect usually will lessen after the first 24 hours or so.

## **Medication Safety Tips**

Medications come in different forms, including pills, liquids, inhalants, patches, suppositories and ointments.

If the patient is having a difficult time swallowing their medication, please notify the Hospice of Marion County nurse. Medicines may be changed into different forms, depending on the patient's needs.

### **Do:**

- Keep medication in its original bottle.
- Read the label before taking the medicine.
- Take medicine exactly as it is written on your prescription or as ordered by your physician and explained by your nurse.
- Avoid alcoholic beverages while taking your medicine. Consult your nurse if you have questions.
- Call your nurse if you have questions regarding the dosage and or medication changes.
- Take your routine medicine on a regular schedule.
- Use your "break-through" medicine as ordered and instructed by your nurse and physician.
- Make sure you have enough medication. Contact your nurse if you think you are running low (less than a 3 day supply).
- Call your nurse if the medicine does not seem to be working.
- Keep suppository medications in refrigerator.
- Pills that are to be given under the tongue will absorb better if put in a small amount of warm water, then under the tongue.
- Notify your nurse if you develop any side effects.
- Keep a written schedule and record when and how often you are taking all your medicine.
- If you are having difficulty swallowing talk to your nurse because some medications may be changed to liquid form or some may need to be given rectally.
- Keep all medicine out of reach of children or pets.

### **Do Not:**

- Take over the counter medication without talking to your doctor or nurse.
- Take more than the amount of medicine that is ordered.
- Share your medications with anyone else, or take anyone else's medication.
- Take medication that does not look right or is expired. Let your nurse know immediately.
- Crush your pills without first checking with your nurse, timed release meds should not be crushed.

### **Helpful Hints:**

- To ease swallowing pills, moisten the mouth with water or add pills to applesauce or pudding. Some pills may be cut in half. Please check with your nurse before crushing any pills since some pills can NOT be crushed.
- If giving a medication rectally, it is best to administer after a bowel movement, if applicable. Using a glove, lubricate one finger and insert the medication at least two thirds of the finger's length.
- When using liquid medicine, slightly tilt the patient's 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 or three drops of water and then place the pills in that area as directed by the nurse.

- Use your hospice folder to store patient education leaflets that come with your medications in addition to your medication list provided by your nurse.

### Comfort Kit:

Hospice of Marion County has several different comfort kits which contain a variety of medications that are used for comfort when different symptoms may occur. If a comfort kit is placed in your home, keep it closed and in the refrigerator (away from the family's food). The nurse will provide directions and instructions on its use when the time is appropriate. Do not open the kit until a Hospice of Marion County nurse instructs you to do so.

### Call the Hospice of Marion County nurse with any questions regarding your medication.

Remember, the nurse is responsible for disposing of unused medication in front of witnesses. In a private home, this is usually accomplished by disposal with cat litter or liquid drug buster. The nurse does not take them into her/his possession to remove them from the home. If you have concerns, please do not hesitate to call the team phone number as noted in the front of this manual.

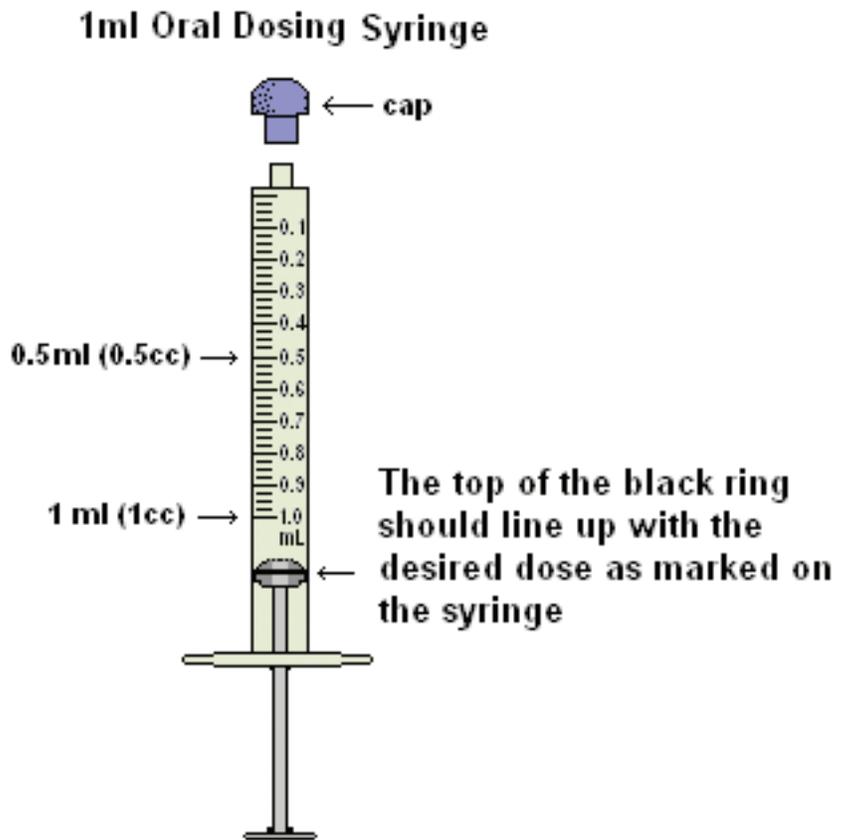
### Measuring Oral/Liquid Medications

The safe and effective use of liquid medications depends on accurate measurements by patients or caregivers. Safety is especially important when you are measuring highly concentrated liquid medications.

Several devices have been developed for measuring liquids. These include oral dosing syringes, oral droppers and plastic measuring cups.

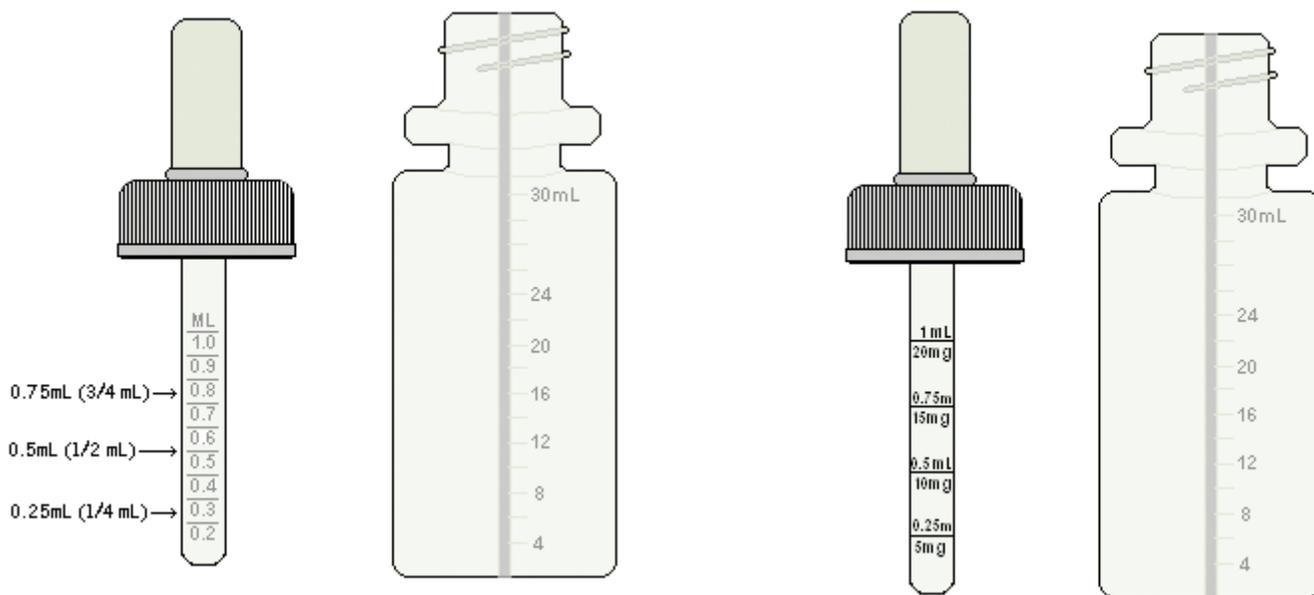
Syringes are usually measured in ccs, tps or ml's (a cc is equal to 1 ml). They come in different sizes. 1ml, 3ml, 10ml, 20ml, 30ml, and 60ml. The smaller syringes (1ml, 3ml, and 5ml) can be used to measure small amounts, even less than 1ml. To be safe, whenever giving a liquid medication, be sure you use the right sized syringe or dropper for the dose of medicine to be given. Always read the label to be sure that you are giving the proper dose. Call Hospice if you have any questions at all, especially if unsure of how much medicine to give. Some medications are measured in fractions of a milliliter (or cubic centimeter). For measuring such small amounts of medicine, you will need to use a 1ml syringe or dropper.

Some medications come with their own dropper. To use it, squeeze the top, put the dropper in the medicine and stop squeezing. The medicine will come up in the dropper. Hold it at eye level to be sure the medicine is at the right line for the dose to be given. Do



not switch droppers from one medicine to the other because they are calibrated to accurately dispense only the medication that they are packaged with.

Examples of droppers that may be used:



## Moving the Patient

### Helping the patient get up to a chair from the bed

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

1. Explain to the patient what you are planning to do.
2. Move slowly.
3. Put the head of the bed up and ensure bed wheels are locked, have the patient turn towards the edge of the bed.
4. Swing the legs down to the floor as you bring the patient to a sitting position. Wait a few moments to allow the patient to adjust to sitting up.
5. Have the chair placed at the head of the bed, facing the foot of the bed.
6. Face the patient and place your right foot between the patient's feet. Keep your back straight, reach under the patient's arms as they place their arms on your shoulder.
7. Hug the patient gently while raising the patient off the bed and pivot the patient towards your left (to the chair).
8. Lower the patient to the chair, bend your knees and keep your back straight.
9. Reverse steps to return the patient to bed.

### Assisting the patient from sitting to the standing position

1. Assist patient in moving to the edge of the bed or chair.
2. Stand directly in front of the sitting patient with your feet shoulder-width apart.
3. Tell the patient to place their hands on your shoulders.
4. Place your hands under patient's arms. Brace yourself by bending knees and keeping your back straight.

5. Straighten yourself, gently raising the patient. Allow the patient to pull on your shoulders.
6. Do not let go unless you are sure the patient is stable.

### **Helping the patient from the bed to a wheelchair or bedside commode**

1. Place the wheelchair or bedside commode next to the bed (at the head of the bed, facing the foot of the bed). LOCK THE BRAKES!
2. Refer to the directions for transferring the patient from sitting to standing.
3. Place your right foot in between the patient's feet.

If you are helping the patient get up or walk and find you can no longer manage the patient, ease the patient to the floor slowly. Make the patient as comfortable as possible before going for help or calling the hospice nurse.

### **Assist the patient to walk**

Before walking with the patient:

- Allow the patient to stand for a few seconds to check for balance and avoid dizziness
- Use a gait belt if available
- Support the patient by placing one arm around their waist or holding their clothes at the waist

### **Walkers**

Some patients may require a cane or walker to assist with safe mobility. Your team member will instruct you how to adjust and use your walker or cane safely. Do not use a walker or cane alone until shown how to properly use the equipment. If the patient feels unsteady, the walker or cane should not be used unless someone else is in the home.

### **Turning a patient from side to side in bed**

1. Begin by always telling the patient what you are going to do before starting the procedure or process. This will decrease fear and anxiety.
2. If the patient is in a hospital bed, raise the side rail on the side toward which the patient will be turned.
3. Move the patient closer to you as you stand at the side of the bed.
4. Move the pillow towards the raised side rail, providing support for the head.
5. Bend the knee that is on top.
6. With your hand on the closest shoulder and hip, turn the patient towards the side rail.
7. Firmly place a pillow behind the back for support.
8. Place another small pillow behind the back for support.
9. Adjust the shoulders, pulling the bottom shoulder slightly out. Add a pillow under the arm.
10. Adjust head pillow for comfort. Ask if the patient feels comfortable. Put up both side rails, cover patient for warmth.
11. At times, it is not unusual for the patient to moan during the turning process. Once the patient has completed the turn, a comfort level will return.

### **Placing a draw sheet**

A draw sheet is useful when a patient can no longer help move themselves. It is a flat sheet or extra-large bath towel placed under the patient and can move the patient without directly pulling on the patient.

1. With the patient lying on their side, place a lengthwise folded sheet along the back, from the shoulders to the thighs. Tuck at least half of this under the patient.

2. Putting the side rail up on the side you have been working on, move to the other side and (put this side rail down) assist patient to roll over the folds of the lift sheet.
3. Straighten out the sheet, smoothing out the wrinkles. Position the patient as desired.

### **Using a draw sheet**

*To turn a patient side to side:*

- Remove any pillows used to support the back and legs. Using the lift sheet, shift the patient towards yourself, then turn patient away from you. Tuck a full-size pillow behind the back. Smooth out the sheets. Position other small pillows or folded sheets between the knees and ankles. Be sure to re-adjust the head pillow and ask the patient if he/she is comfortable.

*To lift a patient to the top of the bed:*

- Use another person, one of you on each side. Each person should grab an edge of the sheet around the shoulder and the edge by the hips. Use a count of three, lift and move up the patient to the head of the bed.

### **Putting the patient on the bedpan:**

1. Put on gloves. Powder the bedpan to avoid any injury to the skin.
2. With the opposite side bed rail up, roll the patient to that side.
3. Place the bedpan squarely on the buttocks.
4. Roll the patient back over the top on the bedpan. Check between the legs to make sure the patient is properly seated on the bedpan.
5. Raise the head of the bed.
6. Put up the other side rail. Stay within calling range or leave a bell nearby.
7. When the patient is done, roll them off the bedpan. Be careful not to let the bedpan tip.
8. Help cleanse the patient and pat dry.
9. Dispose of waste in the toilet, clean out the bedpan.

### **Bathing**

Bathing not only promotes cleanliness, circulation and comfort, but also helps refresh the patient in body and spirit. If the patient has pain, plan to administer pain medication at least 20 minutes before the bath to reduce discomfort. If the patient is in a hospital bed, raise the level of the bed to reduce strain on your back.

#### **What to do:**

1. Assemble all your equipment before starting.
2. Expose only one part of the body at a time as it is being bathed.
3. Beginning with the face, wash with warm water and pat dry.
4. Working from head to feet, including the back, soap an area of skin, rinse well and pat dry.
5. Discard the water after cleansing the feet.
6. Using fresh water, wash genitals and buttocks, working from front to back and drying thoroughly.
7. Make sure all skin folds and crevices are thoroughly dry to prevent chapping.
8. Apply lotion and massage gently. Apply lotion to patient's back and consider giving a back rub.
9. If the patient is unable to tolerate a head to toe bath due to pain or fatigue, attempt a partial bath, washing the face, hands, back and genitals.

## When You Need Help

Hospice of Marion County Certified Nursing Assistants (CNA) are available to assist with personal care when it is needed. Please discuss this with the nurse when he or she visits, or call to talk to a member of your team.

## Skin Care

A person who is bedridden or in a wheelchair for long periods of time puts pressure on the same places, making these areas more likely to develop skin breakdowns. These areas can be made worse when the patient rubs against the sheets, is pulled up in the bed or chair, or if left in urine or bowel movement too long.

Sometimes pressure sores can be prevented if these steps are taken:

1. Explain to the patient the importance of turning frequently.
2. Provide pain medication beforehand as needed so that movement is easier.
3. Use pillows to support the patient in a side-lying position.
4. Keep the skin clean and dry.
5. Keep the bed linens dry and wrinkle free.
6. Use "draw" sheets to move the person, avoiding friction on the skin.
7. Offer to very gently massage around the non-reddened pressure areas.
8. Apply lotion around areas of pressure once or twice each day.
9. Keep heels off bed with pillows under calves.

Check the patient's skin for reddened areas each day during the bath. If you see redness over the pressure areas, tell your nurse. *Do not massage red areas.*

**Even with the best care, skin breakdown may occur. Your nurse will suggest ways to treat these pressure sores and promote skin healing.**

## Itching

Itching can result in restlessness, anxiety, skin sores and infection. Common causes include dry skin, toxins in the food, allergy, and side-effects of medications, chemotherapy and radiation therapy and tumor growth.

## What to Do

1. Apply skin creams with a water soluble base two to three times a day, especially after a bath when the skin is damp.
2. Use warm instead of hot water for bathing.
3. Add baking soda or bath oil to patient's bath water.
4. Wash skin gently using a mild soap.
5. Use baking soda instead of deodorant.
6. Keep patient's nails clean and cut short.
7. Encourage the patient to wear loose clothing made of a soft fabric.
8. Change bed sheets often.
9. Keep room cool (60-70 degrees) and well ventilated.
10. Have patient drink as much water and other fluids as possible, unless otherwise advised by your nurse.
11. Administer medication for itching as ordered by doctor.

## What Not to Do

1. Do not use hot water for baths; use warm water instead, and avoid using harsh detergents.
2. Do not scrub patient's skin.

3. Do not cover patient with a lot of top bedding.
4. Avoid scented and alcohol-based products on skin.
5. Avoid alcohol and coffee.

## **Nutrition**

You may not be able to eat and drink as much as you use to, but eating and drinking regularly can help you feel stronger and have more energy. It is best to focus on eating and drinking food and beverages that bring you comfort and pleasure.

Appetite can be influenced by disease symptoms such as pain, nausea and fatigue. Furthermore, some medications may cause diarrhea or constipation. Our hospice team can help you manage both your feelings and symptoms so that your appetite can become more stable.

Our Dietitian is available for nutrition consultations if you have specific nutrition challenges you would like to discuss.

## **Help with Swallowing Problems**

Swallowing problems may occur with certain diseases or a decline in condition. General signs may include:

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

If you or your loved one is having trouble swallowing, try one or more of the following tips listed below:

1. Try to eat softer foods that require little or no chewing, such as yogurt, pudding, mashed potatoes and scrambled eggs.
2. Add gravies and sauces to pastas, potatoes and ground meats, such as meatloaf.
3. Avoid hot, spicy food and liquids.
4. Avoid common choking foods like corn, rice, nuts, grapes, hot dogs and chips.
5. During eating and drinking, sit in a straight chair at a table, if possible. If you are confined to bed, slightly elevate the head during eating, drinking and sleeping.
6. Have commercial liquid supplements on hand to use as meal replacements when you are not able to eat solid food.
7. Talk with your Hospice of Marion County team. Let them know if you cough or choke when eating or if you are having a hard time swallowing food or fluids.
8. If you need thicker liquids to help with swallowing you can add certain foods or commercially prepared thickening agents which will be determined by your nurse.

## **Mouth Care**

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

### **What to Do**

1. Raise the head of the bed and place a clean cloth under the patient's chin.
2. Remove any dentures and place them in a container of water.
3. Have patient sip water to moisten mouth.
4. Apply toothpaste to the brush and gently brush teeth, gums and tongue.
5. Allow the patient to sip water and spit alternately.
6. Finish with cool water and/or mouthwash, as desired.

7. If dentures were removed, brush them with toothpaste before replacing them into clean mouth.
8. Poor-fitting dentures should be left out of the mouth to prevent mouth sores.
9. Pat lips dry with a clean cloth and apply K-Y Jelly or lip balm to prevent dryness. Reapply moisturizer frequently during the day. Do not use Vaseline if using oxygen.

If the patient is unconscious, unable to swallow or to sit up, do not give mouth care as explained. Your nurse will give you special instructions for mouth care.

## **Diarrhea**

Diarrhea, accompanied by stomach cramping, can be a problem for the hospice patient. If the patient has diarrhea, keep a record of how often it occurs. The nurse will try to find a cause for the diarrhea and will talk to the doctor about how to treat it.

### **What to Do**

1. Offer bedpan at least every two hours, or more often if needed.
2. Increase fluid intake.
3. Have patient sip fluids slowly.
4. Offer the patient clear fruit juices, as well as water.
5. Give frequent small meals instead of three large meals. (Foods that help are oatmeal, strawberries, potatoes, apricots, pears, bananas and rice.)
6. Stop any use of laxatives or stool softeners.

### **Call Hospice of Marion County**

1. If there is blood in the stool.
2. If watery, runny stools 3 or 4 times within several hours.
3. If frequent liquid stools as a change in bowel elimination pattern.

## **Constipation and Bowel Control**

Changes to diet, medication and stress may interfere with patients normal bathroom habits. In addition, the disease itself might involve or interfere with elimination. The best cure for constipation is prevention.

1. Offer fluids often. Hot liquids help bowel activity.
2. Try to provide a diet that includes dietary fiber.
3. Have the patient use the bedpan, commode or toilet at the same time each day.
4. Keep the bedpan or bedside commode near the patient.

### **What to Do**

1. Over-the-counter laxatives and/or stool softeners may be suggested to relieve constipation. Laxatives may be ordered by your doctor and will be instructed by your nurse.
2. Add more high-fiber foods in the daily diet. This includes such things as bran, wheat germ, fresh raw fruits with skins and seeds, fresh raw vegetables, fruit juices, dates, apricots, prunes or prune juice.
3. Increase fluid intake to help prevent dehydration and malnutrition. Fresh fruit juices and warm or hot fluids in the morning are especially helpful.
4. Tell your nurse if the patient has not moved bowels in 3 days.
5. Do not stop taking the bowel medicine once their bowels start moving unless there are three or more bowel movements per day.

## Dehydration

To artificially introduce fluids at this time may overtax the body's heart, lungs and kidneys. It may also increase swelling, vomiting and lung congestion. IVs are not always beneficial or recommended. Frequently IVs only prolong life for a short time, without improving the quality of life or giving comfort.

### Helpful hints:

1. If unable to swallow, offer ice chips or small amounts of water with a straw or syringe.
2. Swab the mouth with toothettes soaked in cool water.
3. Use lip balm to keep lips soft and moist.
4. If there is nausea, vomiting or diarrhea, give medications as directed.
5. Keep the skin clean and dry, but avoid harsh soaps. Apply lotion frequently to keep the skin lubricated.

## Nausea and Vomiting

Nausea can occur even when a person is not thinking about food, and it especially can be a problem the first few days after starting a new pain medication. Vomiting can occur even when there is no food in the stomach. Frequent vomiting can cause the patient to inhale food particles or become dehydrated. The doctor can prescribe medication to help.

1. If the nausea occurs only between meals, give frequent, small meals, snacks at bedtime and leave food within easy reach.
2. Find foods that the patient likes; many times patients don't like the taste of red meat and meat broth. Serve other protein sources.
3. Offer clear liquids served cold and have the patient sip them slowly. (Clear liquids include any fluids you can see through when contained in a glass.)
4. Be sure that your hospice nurse is aware of the problem. Medications can be ordered to relieve these symptoms, and your nurse will instruct you on how and when to give them.
5. Have the patient rest comfortably in a quiet place.
6. Provide distraction, such as soft music, a favorite television program or stay and keep the patient company.
7. Provide good mouth care.

### If the Patient is Vomiting

1. If the patient is bedridden elevate the head and back and be sure he or she is moved on his or her side, so the vomit will not be inhaled.
2. Provide liquids in the form of ice chips or frozen juice chips.
3. Give sips of ginger ale or peppermint tea.
4. Keep a record of how often and how much the patient vomits.

### What Not to Do

1. Do not force foods or fluids on a patient who is nauseated or vomiting.
2. Do not allow the patient to lie flat on his or her back.

**If the patient is vomiting frequently, do not allow patient to eat for 4-8 hours, then, start with clear liquids.**

## **Call Hospice of Marion County**

1. If you are concerned that some of the vomited material has been inhaled.
2. If the vomiting occurs more than 3 times an hour for 2 or more hours.
3. If any blood or material that looks like coffee grounds appears in the vomit.
4. If the patient is unable to take his or her medications.
5. If the patient feels unusually weak or dizzy.
6. If the patient loses consciousness.

## **Elimination of Urine**

Some patients are not able to control urination. In others, the urine can't move through the body the way it should.

If either of these conditions is present, the nurse may need to place a catheter (tube) into the patient's bladder to drain the urine. This will only be done at the direction of the doctor, after the nurse has talked to the patient and family. If everyone agrees that a catheter is needed, the nurse will put it in place, teach the patient and family how it works and how to take care of it. Diapers or external catheters (male patients only) are other options.

### **What to Do**

1. Offer all types of fluids to the patient. (Tea, coffee and cranberry juice have a diuretic effect, but include all types of liquids.)
2. Help start urine flowing by running water, pouring warm water over hands and genitals, having patient drink a glass of water or gently massaging the lower abdomen over the bladder.

### **What Not to Do**

1. Do not give the patient fluids if he or she does not urinate after 12-14 hours.
2. Do not force the patient to drink if he or she feels unable to do so.

## **Call Hospice of Marion County**

1. No urine for more than 12-14 hours.
2. The patient's abdomen appears bloated.
3. The patient complains of pain in the lower abdomen or in the mid back.
4. Pain, burning or foul odor after urinating.

## **Urinary Catheter Care**

### **What is a urinary catheter?**

A urinary catheter is used when you cannot urinate by yourself. It is a tube inserted into the bladder which is kept in place by a small balloon that is inflated once the tube is securely in the bladder. The nurse will connect the tube to a drainage bag. Urine will be seen in the tube as it drains into the bag.

### **Things to Remember about Urine Drainage Systems**

1. Check the drainage tubing for any kinks and make sure the drainage bag is below the level of the patient to encourage draining.
2. Make sure the urinary drainage bag does not pull on the catheter, drag or touch the floor.
3. Do not apply powder or lotion to the area where the catheter enters the body.
4. The drainage bag should be emptied one or more times per day.

## **How to Care for the Catheter**

1. Wash your hands, put on disposable gloves.
2. Clean the area where the catheter enters the body with a washcloth, soap and water twice each day.
3. Rinse well and dry with a clean towel.
4. If the patient is active, help the patient with the tubing and drainage bag, using care not to tug or pull on the drainage tube. The nurse can show you how to secure the catheter.
5. Be sure tubing is straight and free of kinks so the urine drains continuously into the drainage bag.
6. Always place the drainage bag below the level of the bladder to aid in draining.
7. Remove disposable gloves, wash your hands.

## **How to Drain the Urine Collection Bag**

You will need to empty the bag at regular intervals, whenever it is half full, and at bedtime.

1. Wash your hands with soap and water, put on disposable gloves.
2. Unfasten the tube from the drainage bag.
3. Fasten the tubing clamp and remove the drainage cap.
4. Drain the urine into a container and then empty it into the toilet.
5. Replace the drainage cap, close the clamp, and refasten the collection tube to the drainage bag.
6. Place the drainage bag below the level of the patient to aid in draining.
7. Clean the collection container.
8. Remove disposable gloves, wash hands with soap and water.

## **Call Hospice of Marion County**

1. If no urine or very little urine is flowing into the collection bag for 4 hours or more.
2. If the urine has changed color, is very cloudy, looks bloody, has large blood clots in it, or it has a foul odor.
3. If urine is leaking from the insertion site.
4. If there are signs of redness or irritation of the skin around the catheter.

## **Irrigating the Catheter**

### **If a catheter becomes blocked, irrigating the catheter can restore the flow of urine.**

Catheter blockage should be suspected if urine flow has stopped and there are no kinks in the lines and the collection bag is below the level of the patient.

### **CALL THE NURSE BEFORE ATTEMPTING TO IRRIGATE FOR THE FIRST TIME**

#### **Things You Will Need:**

1. Irrigation tray and syringe (provided by Hospice of Marion County).
2. Sterile saline solution.
3. Alcohol wipes.
4. Waterproof bed pad.
5. Disposable gloves.

#### **How to Irrigate the Catheter:**

1. Always call the nurse prior to the first time you plan to irrigate.
2. Wash your hands well, put on disposable gloves.

3. Place a waterproof bed pad under the work area to protect the bed linens from any spilled urine.
4. Pour sterile saline into the irrigating container (about ½ cup).
5. Remove the cap from the syringe and fill syringe ¼ to ½ full with sterile saline from the container. Push the tip of the syringe into the catheter until it fits snugly.
6. Gently push the solution into the catheter. If you meet a lot of resistance, stop and reconnect the tubing to the catheter. Notify your nurse.
7. If the solution goes in easily (as it should), disconnect the syringe and let the catheter drain into irrigation tray container.
8. Replace the cap on the syringe and discard.
9. Reconnect the catheter to the drainage bag and tubing.
10. Dispose of urine and any unused saline into the toilet.
11. Remove disposable gloves, wash your hands.

## **Agitation**

Agitation generally means a sudden, distressing state of intense restlessness. The patient seems to have a short attention span and there seem to be changes in one's ability to think clearly. This often occurs in nearly half of all patients in the last 48 hours of life. There are several things that can cause agitation, including an inability to empty the bladder, constipation, dehydration, shortness of breath, pain, withdrawal of alcohol or nicotine if there has been a history of such addiction, fever or chemical imbalance.

Call Hospice of Marion County if the patient suddenly begins to act agitated. The best treatment for agitation usually includes several approaches, only one of which is medication.

## **Breathing Care**

A number of health problems may make it hard for the patient to get oxygen into the lungs. This can cause the patient to have shortness of breath.

Other symptoms of low body oxygen are restlessness, anxiety, increased heart rate, increased breathing rate or a bluish color to nails and lips. When a patient has shortness of breath, he or she may become anxious or frightened. It is important for the caregiver to be calm and reassuring. Help the patient to be aware of the breathing process, to slow it down and to breathe deeply.

## **What to Do**

1. Move patient to a 45-degree angle by raising the head of the bed or using pillows.
2. If oxygen or inhalers are prescribed, be sure they are in use. Other medication may be prescribed to also help the breathing discomfort.
3. Look the patient in the eye and kindly remind them to breathe in through the nose and out through the mouth.
4. Encourage the relaxation of the shoulders, back and arms. Use touch and massage if the patient agrees this will help.
5. Some patients feel better with an open window or with a fan blowing on them.
6. In hot, humid weather, set the air conditioner to lower humidity.

If there is no relief after 5 minutes of breathing difficulty, have patient sit on the side of the bed with feet resting on a stool, arms resting on an over bed table and head tilted slightly forward. If patient is coughing and spitting, note the amount of sputum and what it looks and smells like (normal is clear or white and foamy).

## Call Hospice of Marion County

If the patient has continued shortness of breath and isn't any better after following the directions listed above.

## Secretions or Rattled Breathing

Often during the last days of life, the patient is too weak to clear secretions or drainage that is in the airways. Air moving through these secretions can cause a "rattling" sound, which is sometimes called the "death rattle".

These sounds may be upsetting to others, but the patient is usually in a coma-like state and is not aware of what is happening. The gurgling or rattling does not cause the patient distress. Breathing may become irregular and there may be pauses between breaths. Sometimes these pauses may last for several seconds. At this time, you may notice cooler, bluish extremities. This is the result of less oxygen in the blood. Certain things can be done to keep your loved one most comfortable, and to help this time period be less distressing for all.

## Things You Can Do

1. Keep the head of the bed up, which will help make breathing easier.
2. Turn the patient from one side to the other every 2-3 hours so secretions can drain.
3. Continue frequent mouth care to help keep the mouth moist and clean.
4. Use toothettes (mouth sponges) and small amounts of mouth rinse or cool fluid to cleanse the mouth.
5. Do not try to force the patient to swallow fluids.
6. Sometimes a medicine is ordered that helps dry secretions. This medicine is usually given under the tongue every 2-3 hours, as instructed by your nurse. Continued doses are usually necessary for the medicine to be most effective. Your nurse will give specific instructions if this is a medicine that you will be given.

Suctioning is not helpful; this is usually irritating and causes discomfort. The mucous that is removed will only re-accumulate.

## Fluid Retention

Patients often retain fluid in their legs, ankles, feet, hands and other places. This is called edema. The doctor or nurse who is familiar with the patient may be able to give you more information. Here are four common causes of edema:

1. The heart is weaker.
2. There is less protein in the diet.
3. There is less moving around.
4. Pressure from tumors.

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

1. Elevate the affected area above the heart if possible, and if not, elevate as able.
2. Avoid tight clothing, belts, socks, rings or shoes.
3. It may be helpful to avoid salt. Check foods for high-salt content.
4. The doctor may order a "water pill" – a diuretic, to excrete excess water.
5. Move around as able.
6. Have the nurse show range-of-motion exercises if the patient is bed bound.

## Prevention of Bleeding

Patients may be more likely to bleed because of the effects of their illness. Talk with the Hospice of Marion County nurse if there is any unusual bleeding. The following are guidelines to assist in the prevention of bleeding:

1. Avoid using sharp objects.
2. Use an electric shaver.
3. Use a soft toothbrush, sponge "toothpaste," or a washcloth to clean teeth. Floss carefully.
4. Rectal medicine should be given carefully and with a generous amount of water-soluble lubrication.
5. Injections should be avoided.
6. Blow nose gently, and sneeze with your mouth open.
7. Move furniture out of the way. Turn lights on.
8. Wear a seat belt in the car.
9. Always wear slippers or shoes when out of bed.
10. If bleeding is probable to occur, it is helpful to have dark towels on hand to absorb blood.
11. Avoid straining to have a bowel movement. Discuss the use of stool softeners with your nurse.

### **Report any of the following observations to your nurse.**

1. Blood in the urine, stool, sputum or vomit.
2. Black stools (tar like).
3. Vomit that is dark brown or bright red.
4. Bloody nose (one that is difficult to control) or bleeding gums.
5. Multiple bruises.
6. Many small, reddish-purple dots under the skin.

Alert nurse if you are taking aspirin or aspirin containing products, as this may need to be held if bleeding continues to be a problem.

### **Call Hospice of Marion County**

If bleeding occurs, apply pressure if this is possible.

## Care of Patients Having Seizures

Seizures appear as facial twitches, tremors in one or more areas of the body or a convulsion of the entire body. Seizures generally last a few minutes or less. You cannot stop a seizure once it has started. You can help a patient during a seizure by doing the following:

1. KEEP CALM
2. Protect the patient from injury by:
  - Easing patient to the floor or bed if patient is standing.
  - Padding the bedrails (use towels, blankets, pillows, etc.).
  - Removing sharp or hard objects near the patient.
3. Help the patient by:
  - Turning head to side if secretions are present.
  - Loosening constricting clothing such as belts or ties.
  - Placing something soft under the patient's head.

#### 4. DO NOT

- Force anything between the teeth.
- Put your fingers in the patient's mouth.
- Interfere with the patient's movements unless it's essential for personal safety.

#### 5. Allow the patient to rest after seizure has subsided.

## Section 8 • Medical Equipment

The Hospice of Marion County nurse will evaluate the need for medical equipment and arrange delivery. Oxygen is a drug that requires a prescription prescribed by your physician. It must be used as ordered for the patient only. All safety, maintenance and operating instructions must be followed as directed by the medical equipment company known as Accent Medical and reinforced by Hospice of Marion County, Inc.

When the equipment is no longer needed, the nurse will arrange for pickup through the medical equipment company. If you must have the equipment removed earlier than the next business day, call Hospice of Marion County to coordinate this with the medical equipment company.

### Oxygen Concentrator

#### How to use the oxygen concentrator:

1. Read the patient instruction sheet thoroughly.
2. Keep your concentrator at least 12 inches away from any object as instructed by the manufacturer.
3. Plug the concentrator into the wall outlet that was tested by the company representative. DO NOT USE a plug that is shared with other appliances. DO NOT USE an extension cord unless authorized by the manufacturer and/or your equipment supplier.
4. Attach all equipment prior to use. If humidification is required, put distilled water into the humidifier bottle.
5. Attach tubing to humidifier along with cannula using connector. If you are not using humidity, leave bottle off and attach the cannula to the oxygen outlet. Use the adapter if necessary. Oxygen tubing cannot exceed 60 ft. in length.
6. Make sure that all filters are clean, dry and in place.
7. Turn the power button to the "on" position.
8. Set the prescribed liter flow. Do not turn the liter flow knob below 0 or above 5 liters. If you have a 10 liter concentrator, do not turn the liter flow knob below 0 or above 10 liters. Setting the liter flow too low or too high will set off the alarm and shut down the concentrator. Now adjust your cannula to a proper fit.
9. Power light should be illuminated.
10. The green indicator light should turn on within 3-5 minutes, or sometimes less. If the unit is not working properly, you will see either the Yellow or Red indicator light go on.

#### What to do when the concentrator is not working:

1. Make sure the concentrator is plugged into the outlet checked by the equipment supplier. Check to be sure the plug has a secure fit.
2. Make sure the electricity is turned on to the outlet. (Not on a light switch)
3. Check the reset button located on the face of the machine.
4. Turn the machine off, wait a few seconds and turn the machine to the on position.

5. Make sure the flow meter is turned on to prescribed rate. Do not turn the liter flow knob below 0 or above 5 liters. If you have a 10 liter concentrator, do not set the flow meter below 0 or above 10 liters. Setting the liter flow too high or too low will set off the alarm and shut down the concentrator.
6. Make sure the oxygen cannula is not pinched off and that the tubing is connected securely to the humidifier bottle.
7. Check that the humidifier bottle is secure and that the lid is screwed on properly.
8. Call the nurse for assistance if you are still experiencing problems. The telephone number is located in the Quick Reference Guide in the front of this book. If after business hours, the hospice On-Call staff will assist you. Use your oxygen cylinder at the prescribed liter flow until your concentrator is repaired or replaced.

### **Maintenance of Concentrator:**

1. Keep equipment clean by using a damp cloth. DO NOT USE chemicals. Always unplug the unit when cleaning.
2. Empty all the water out of the humidifier bottle before you refill it using distilled water.
3. Change the humidifier bottle and tubing every month or as needed.
4. Change the cannula every 2 weeks unless you have a cold, then change it every week or as needed.
5. If not using concentrator, water should be emptied out of humidifier bottle to prevent bacterial growth and the bottle should be air dried before storing.
6. Cleaning of the outside air filter should be done at least once weekly. (Black foam) Wash it with soap and water, rinse it, pat it dry, and put back on the concentrator.

# Section 9 • As the Patient's Condition Changes

## Food and Fluids at the End of Life

Most dying patients feel little hunger. They eat and drink very little or refuse all food and fluids. As a family member, remind yourself that this is not a healthy person refusing to eat and experiencing hunger pains. Adding food and fluids to a dying body may cause stress.

When disease progresses and death approaches, organs decrease their normal level of functioning. When a person is fed at this point, the body is unable to process food and fluids normally. The outcome may be discomfort and increased suffering, with symptoms such as swelling, bloating, choking, coughing, nausea, vomiting or difficulty breathing. Please keep in mind that feeding through a tube or IV is also giving food and fluids.

To artificially introduce fluids at this time may overtax the body's heart, lungs and kidneys. It may also increase swelling, vomiting and lung congestion. IVs are not always beneficial or recommended. Frequently IVs only prolong life for a short time, without improving the quality of life or giving comfort.

### Helpful Hints:

1. If unable to swallow, offer ice chips or small amounts of water with a straw or syringe.

## As the Time of Death Nears

Many families have questions and concerns about what the patient's death will be like. Hospice staff realizes that this particular period of time is one of the most difficult times that families will have to live through.

The expected manner of death for any individual depends upon many things, including the specific diagnosis, the way a disease progresses and which body systems seem to be failing most quickly. Members of your hospice team will tell you as much as possible about what the death experience will be like, but sometimes we do not know until fairly close to the end. Here is some general information about what changes you might see:

### Appetite

The appetite will decrease, if it hasn't already. A lack of interest in food and fluids will progress to an inability to swallow. This is because body functions are slowing down gradually and the resulting dehydration actually increases the patient's comfort, although it is important to give mouth care. Efforts to force a patient to eat will only result in the uncomfortable symptoms of nausea and vomiting or even stomach pain.

### Increased Periods of Sleeping

This symptom is one of the first symptoms you will witness. It is a result of the change in the body's metabolism and the progression of the disease process. The person will gradually spend more time sleeping during the day and at times be difficult to arouse.

### Incontinence

Incontinence (loss of bladder and bowel function) is commonly seen when a patient is no longer strong enough to get out of bed. There will be a decrease of output with the urine becoming darker.

### Skin Mottling

There may be an increase in body temperature, while at the same time the hands and feet become cooler, maybe even bluish or mottled. These symptoms are the result of blood circulation slowing down. Typically, neither the raised temperature nor the coolness and mottling are distressing to the patient.

## **Congestion**

Mucus may collect in the mouth, throat or lungs. This symptom is a result of the inability to cough up normal saliva production or it may be due to the relaxation of the muscles of the back of the throat. Elevating the head of the bed will make breathing easier or turning the patient to lay on his/her side usually relieves this. Suctioning is NOT recommended as it is very distressing to the patient, as well as being a futile effort.

## **Changes in Breathing**

You may notice a change in the person's breathing patterns. You may see 10-30 second periods of no breathing, referred to as apnea. The symptom is very common, signaling a decrease in circulation and a buildup of body waste products.

## **Dehydration**

This often occurs as part of the natural dying process and is not painful. Causes may include loss of appetite, difficulty swallowing, nausea or vomiting, diarrhea or use of water pills.

## **Communication**

Communication with others usually decreases as the patient becomes weaker and sleepier. However, even when the patient becomes too weak to speak or becomes unconscious, she or he can still hear as hearing is the last sense to be lost.

## **Restlessness**

You may notice the patient becoming restless, pulling at bed linens, picking at the air, having visions or talking to people who do not exist to you. These symptoms can be a result of a decrease in oxygen circulation to the brain and a change in the metabolism.

# **The Vigil**

Until now, your loved one may have been in the pre-active phase of dying. That may last an average of two weeks. As death nears, it may seem the person is "turning a corner." This may be the start of the active phase of dying, or the vigil. It lasts about three days, though these time frames can be longer or shorter.

For example, all medications are probably streamlined to only those that provide comfort. Usually the dying person is in some level of a coma and cannot swallow, so medications are given by other routes. Many of the signs mentioned in this booklet are noted by now.

As some or all of these changes occur, the dying person may seem more withdrawn from the outer world. The vigil is the time when we truly realize that we are not in control of the dying process. Death is very near. We cannot answer with certainty questions of "How much longer?" During the vigil, we watch, we comfort, and we wait. Like birth, death comes in its own way, at its own time.

Though difficult, it may be important to tell your loved one, in your own words, "I'll miss you. But I can let you go out of love." Likewise, though probably unable to speak, the dying person may wish to say, "I love you and I don't want to leave, but I need to let go. Will you be all right? May I go?" It is comforting for the person to be assured of your love and presence at that moment, as well as your well-being after the death.

Families often wonder if the dying person hears them or is aware of their presence. As death nears, it may seem your loved one has already left you. The dying person probably can hear; and possibly has a more expanded awareness than the physical senses can allow. Why not believe that your best intentions are known by your loved one, whether you speak them or not? Allow yourself to be open to possibility. As you walk closer to the threshold of death, take heart in what a profound gift it is to accompany your loved one on this journey.

# Section 10 • Cardiopulmonary Resuscitation (CPR)

Patients meeting eligibility criteria are admitted with the understanding of the hospice philosophy, which:

1. Focuses on comfort – not on curing an illness or disease.
2. Does not hasten death.
3. Does not prolong a person's suffering.
4. Allows most patients to die in a home-like environment instead of a hospital.

Studies shown that end-stage patients who survive resuscitation and are put on life-support machines may have greater difficulty being removed from machines, if at all. Less than 10% of chronically ill patients survive CPR and even less have intact brain function after being resuscitated. Inducing more suffering through resuscitation and artificial life support is not part of the hospice philosophy.

## **What happens if there is no signed Do Not Resuscitate (DNR) order?**

By Florida law, Hospice staff and/or Emergency Medical System (EMS) personnel WILL start CPR (Cardiopulmonary Resuscitation) if there is no signed DNR order. Chest compressions will be started on a patient with no pulse.

## **What happens if there is a signed DNR order present when 911 is called?**

The Emergency Medical System (EMS) personnel will NOT start CPR. If you do not have a signed Do Not Resuscitate Order, hospice will help you obtain one. *Allow Natural Death* is another way of thinking of the meaning of a DNR Order.

# Section 11 • Health Care Advanced Directives

An advanced directive is a witnessed oral or written statement regarding medical decisions in the event you are unable to make them yourself. It may also express your wish to make an anatomical donation after death. Types of advanced directives are:

1. Living Will.
2. Health Care Surrogate Designation.
3. Durable Power of Attorney for Health Care Decisions.
4. Do Not Resuscitate Order (DNRO).
5. Anatomical Donation.

Living Will and Health Care Surrogate forms are located in your admission packet or from your social worker.

## Section 12 • Final Arrangements

Hospice of Marion County's staff does not make recommendations regarding funeral homes or cremation services. However, your social worker can help by showing you a listing of those available in the area. Types of services are:

1. Funeral services
2. Burial
3. Cremation
4. Burial at Sea

Our chaplains can assist you in planning a memorial service for your loved one, and are also available to conduct the funeral or memorial service.

## Section 13 • Striving for Excellence

### Providing Excellence to You and Your Family

We really appreciate you allowing us to provide “**excellent**” care and services for you and your family at this time in your lives. We strive to provide “**excellent**” care and to exceed your expectations in all areas, some of those include:

1. Adequate medication received to manage pain and/or other discomfort.
2. Personal care such as bathing and dressing are provided as needed.
3. One nurse identified as being in charge of you/your loved one's care.
4. Confident doing what was needed to take care of patient.
5. Delivery of home medical equipment was prompt.
6. Equipment delivered in good working order.
7. Hospice team responds to needs in the evening or weekend.
8. Overall, the care provided is excellent.

One tool we use to monitor excellence is the family satisfaction survey that will be sent at the appropriate time. If at any time a patient or caregiver has a question or feels that the care and services received are not exceeding the **excellent** standard, please contact a staff member of Hospice of Marion County immediately so that the concern can be addressed. Many times an answer or solution can be found instead of waiting for a survey to arrive and then address the problem.

# Section 14 • Complaint Process/Speak Up Program

## Speak Up Program

**S**peak up if you have questions or concerns, and if you don't understand, ask again. It's your body and you have a right to know.

**P**ay attention to the care you are receiving. Make sure you're getting the right treatment and medications by the right hospice staff.

**E**ducate yourself about your diagnosis, the services the hospice organization will be providing to you, and your careplan.

**A**sk a trusted family member or friend to be your advocate.

**K**now what medications you take and why you take them. Medication errors are the most common health care mistakes.

**U**se a hospice organization that has undergone a rigorous on-site evaluation against established, state-of-the-art quality and safety standards.

**P**articipate in all decisions about your treatment and the hospice services you are receiving. You are the center of the hospice care team.

### Abusive Practices are not Tolerated

If you experience treatment that you feel is abusive, neglectful or exploitive, please call and report any incident at the following toll-free hotline: 1-800-96ABUSE or 1-800-962-2873.

### Patient and Family Complaint Procedure

We stand by the quality of our care. If you have a concern or complaint, notify any staff member of your complaint, who will immediately strive to resolve your complaint. You may also contact a Quality Improvement Representative at (352) 873-7400. If you have further concerns, you may contact the Agency for Health Care Administration at (888) 419-3456 or The Joint Commission by calling 1-800-994-6610, contacting them online: [www.jointcommission.org/reportacomplaint.aspx](http://www.jointcommission.org/reportacomplaint.aspx); fax 1-630-792-5636 or email [complaint@jointcommission.org](mailto:complaint@jointcommission.org).

# Section 15 • Gifts to Hospice of Marion County

## Your Gift Helps Us Help Others

Because of the excellent care and services that they received, many patients and families ask us how they can help Hospice of Marion County in return. Here are four significant ways to make a difference.

1. Tell others about the excellent care and service provided by the great staff of Hospice of Marion County.
2. When it is the right time, become a Hospice of Marion County Volunteer to help others through this life-changing experience.
3. Donate gently used items to our Thrift Stores. Call (352) 873-7441 with questions; to schedule a pick-up call (352) 512-8585.
4. Notify family and friends that in lieu of flowers, a donation to Hospice of Marion County as a memorial is gratefully appreciated.

Special recognition opportunities are available at The Elliott Center as well as at our four hospice houses. For information about special memorials, honoraria or questions regarding any gifts or donations, call the Philanthropy Department at (352) 854-5218. They will be happy to help.

For your convenience, Hospice of Marion County accepts contributions by check, Visa, MasterCard, Discover or other types of monetary transfer. Secure donations may also be made online at [www.hospiceofmarion.com](http://www.hospiceofmarion.com). Hospice of Marion County is a 501(c) (3) non-profit organization.

A copy of the official registration and financial information may be obtained from the division of consumer services by calling toll-free 1-877-693-5236 within the state or at [www.myfloridacfo.com/Division/Consumers/](http://www.myfloridacfo.com/Division/Consumers/). Registration does not imply approval, or endorsement or recommendation by the state. Disclaimer Registration #CH1781.

Every gift is a tax-deductible donation and gratefully accepted by Hospice of Marion County.

# Section 16 • Veterans Remembered

## Recognition Ceremony

With more than 46,000 veterans living in Marion County, Hospice of Marion County, in conjunction with the Hospice Veteran's Partnership of Florida, offers special recognition to veterans, upon request, in the form of a unique pinning ceremony.

The event can be as large or small, formal or informal as you would like. Some veterans and their families may decide to hold a gathering of loved ones and friends, while others may prefer a more private experience. It is your choice.

Veterans receive a special certificate of appreciation, a unique Honored Veteran lapel pin and a miniature flag stand representing the United States, the State of Florida and the military branch in which the patient served. The ceremony is conducted by current or former military personnel and is a moving tribute to those whose sacrifice is the foundation of the freedom we enjoy today.

## Wall of Honor

A permanent recognition are the four Walls of Honor, tributes to loved ones, either living or departed. Employees, volunteers, patients or their families may be recognized. An honoree's name and insignia of the branch of the service is laser-engraved on a polished black plate installed on a flag-shaped wood plaque. Contact the Philanthropy Department at (352) 854-5218.

## Resources

Florida National Cemetery  
Bushnell Sumter County, Florida  
6502 SW 102nd Avenue  
Bushnell, Florida 33513  
(352) 793-7740  
(352) 793-1074

Marion County Veterans Services  
2528 East Silver Springs Blvd.  
Ocala, Florida  
(352) 671-8422

Veteran's Affairs Community-Based Outpatient Clinic  
1515 East Silver Springs Blvd.  
Ocala, Florida  
(352) 369-3320

# Section 17 • Notice of Privacy Practices

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

## USE AND DISCLOSURE OF HEALTH INFORMATION

Hospice of Marion County Inc. (HMC) may use your health information, information that constitutes protected health information as defined in the Privacy Rule of the Administrative Simplification provisions of the Health Insurance Portability and Accountability Act of 1996, for purposes of providing you treatment, obtaining payment for your care and conducting health care operations. HMC has established policies to guard against unnecessary disclosure of your health information.

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

**To Provide Treatment.** HMC may use your health information to coordinate care within the HMC and with others involved in your care, such as your attending physician, and other health care professionals who have agreed to assist HMC in coordinating care. For example, physicians involved in your care will need information about your symptoms in order to prescribe appropriate medications. HMC also may disclose your health care information to individuals involved in your care including family members, clergy who you have designated, pharmacists, suppliers of medical equipment or other health care professionals.

**To Obtain Payment.** HMC may include your health information in invoices to collect payment from third parties for the care you receive from HMC. For example, the HMC may be required by your health insurer to provide information regarding your health care status so that the insurer will reimburse you or HMC. HMC also may need to obtain prior approval from your insurer and may need to explain to the insurer your need for care and the services that will be provided to you.

**To Conduct Health Care Operations.** HMC may use and disclose health information for its own operations in order to facilitate the function of your care and as necessary to provide quality care to all of the HMC's patients. Health care operations include such activities as:

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

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

**For Bereavement Services.** HMC may use and disclose health information as deemed necessary to accomplish the objectives of bereavement counseling services to your family/friends or those that were involved in your care.

**For Fundraising Activities.** HMC may use information about you including your name, address, phone number and the dates you received care in order to contact you or your family to raise money for HMC. HMC may also release this information to a related HMC foundation. If you do not want HMC to contact you or your family, you may opt out by notifying the Philanthropy Department in writing at P.O. Box 4860, Ocala, FL 34478, and indicating that you do not wish to be contacted. You may also opt out by calling us toll free at 1-888-428-5018.

**For Marketing Activities.** HMC will occasionally ask patients and families to share their stories or comments in regards to services received. Before this may happen you or your representative will be asked to provide consent for the specific use.

**For Appointment Reminders.** HMC may use and disclose your health information to contact you as a reminder that you have an appointment for a home visit.

**For Treatment Alternatives.** HMC may use and disclose your health information to tell you about or recommend possible treatment options or alternatives that may be of interest to you.

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

**When Legally Required.** HMC will disclose your health information when it is required to do so by any Federal, State or local law.

**When There Are Risks to Public Health.** HMC may disclose your health information for public activities and purposes in order to:

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

**To Report Abuse, Neglect Or Domestic Violence.** HMC is allowed to notify government authorities if HMC believes a patient is the victim of abuse, neglect or domestic violence. HMC will make this disclosure only when specifically required or authorized by law or when the patient agrees to the disclosure.

**To Conduct Health Oversight Activities.** HMC may disclose your health information to a health oversight at HMC for activities including audits, civil administrative or criminal investigations, inspections, licensure or disciplinary action. HMC, however, may not disclose your health information if you are the subject of an investigation and your health information is not directly related to your receipt of health care or public benefits.

**In Connection With Judicial And Administrative Proceedings.** HMC may disclose your health information in the course of any judicial or administrative proceeding in response to an order of a court or administrative tribunal as expressly authorized by such order or in response to a subpoena, discovery request or other lawful process. HMC will make reasonable efforts to obtain assurance from the entity delivering the order that steps have been taken to notify you.

**For Law Enforcement Purposes.** As permitted or required by State law, HMC may disclose your health information to a law enforcement official for certain law enforcement purposes as follows:

- As required by law for reporting of certain types of wounds or other physical injuries pursuant to the court order, warrant, subpoena or summons or similar process.
- For the purpose of identifying or locating a suspect, fugitive, material witness or missing person.
- Under certain limited circumstances, when you are the victim of a crime.
- To a law enforcement official if the HMC has a suspicion that your death was the result of criminal conduct including criminal conduct of the HMC.
- In an emergency in order to report a crime.

**To Medical Examiners.** HMC may disclose your health information to medical examiners for purposes of determining your cause of death or for other duties, as authorized by law.

**To Funeral Directors.** HMC may disclose your health information to funeral directors consistent with applicable law and if necessary, to carry out their duties with respect to your funeral arrangements. If necessary to carry out their duties, HMC may disclose your health information prior to and in reasonable anticipation of your death.

**For Organ, Eye Or Tissue Donation.** HMC may use or disclose your health information to organ procurement organizations or other entities engaged in the procurement, banking or transplantation of organs, eyes or tissue for the purpose of facilitating the donation and transplantation.

**For Research Purposes.** HMC may, under very select circumstances, use your health information for research. Before HMC discloses any of your health information for such research purposes, the project will be subject to an extensive approval process. Your written authorization is required for all other research purposes.

**For Specified Government Functions.** In certain circumstances, the Federal regulations authorizes HMC to use or disclose your health information to facilitate specified government functions relating to military and veterans, national security and intelligence activities, protective services for the President and others, medical suitability determinations and inmates and law enforcement custody.

**For Worker's Compensation.** HMC may release your health information for worker's compensation or similar programs.

**AUTHORIZATION TO USE OR DISCLOSE HEALTH INFORMATION**

Uses and disclosures of your protected health information that involve marketing, sale of your protected health information, certain research purposes, or any other uses and disclosures not described in this notice or required by law will be made only with your written authorization. If you or your representative authorizes the HMC to use or disclose your health information, you may revoke that authorization in writing at any time.

**YOUR RIGHTS WITH RESPECT TO YOUR HEALTH INFORMATION**

You have the following rights regarding your health information that the HMC maintains:

- **Right to request restrictions.** You may request restrictions on certain uses and disclosures of your health information. You have the right to request a limit on the Hospice of Marion County's disclosure of your health information to someone who is involved in your care or the payment of your care. HMC must comply with your request if the disclosure is to a health plan for purposes of carrying out payment or health care operations (and is not for the purpose of carrying out treatment) and the protected health information pertains solely to a health care item or service for which the health care provider involved has been paid out of pocket in full by you. Otherwise, HMC is not required to agree to your request. If you wish to make a request for restrictions, contact the Privacy Official in writing at P.O. Box 4860, Ocala, FL 34478.

- **Right to receive confidential communications.** You have the right to request that the HMC communicate with you in a certain way. For example, you may ask that the HMC only conduct communications pertaining to your health information with you privately with no other family members present. If you wish to receive confidential communications, please contact the Privacy Official in writing at P.O. Box 4860, Ocala, FL 34478. The HMC will not request that you provide any reasons for your request and will attempt to honor your reasonable requests for confidential communications.
- **Right to inspect and copy your health information.** You have the right to inspect and copy your health information, including billing records. A request to inspect and copy records containing your health information may be made in writing to the Privacy Official at P.O. Box 4860, Ocala, FL 34478. If you request a copy of your health information, HMC may charge a reasonable fee for copying and assembling costs associated with your request. You have the right to request a copy of your health information that is maintained electronically in an electronic format if it is readily producible. You also have the right to request HMC to transmit a copy of this information directly to a designated third party on your behalf. We may charge a reasonable fee for producing the electronic copy of your health information.
- **Right to amend health care information.** You or your representatives have the right to request that HMC amend your records, if you believe that your health information is incorrect or incomplete. That request may be made as long as the information is maintained by the HMC. A request for an amendment of records must be made in writing to the Privacy Official, P.O. Box 4860 Ocala, Florida 34478. HMC may deny the request if it is not in writing or does not include a reason for the amendment. The request also may be denied if your health information records were not created by HMC, if the records you are requesting are not part of the HMC's records, if the health information you wish to amend is not part of the health information you or your representative are permitted to inspect and copy, or if, in the opinion of HMC, the records containing your health information are accurate and complete.
- **Right to an accounting.** You or your representative have the right to request an accounting of disclosures of your health information made by the HMC for certain reasons, including reasons related to public purposes authorized by law and certain research for a period of up to six (6) years prior to the date of the request. You also have the right to request an accounting of disclosures of your health information for the purposes of treatment, payment, or healthcare operations for a period of up to three (3) years prior to the date of the request for disclosures made after January 1, 2014. The request for an accounting must be made in writing to the Health Information Privacy Official at P.O. Box 4860, Ocala, FL 34478. HMC would provide the first accounting you request during any 12-month period without charge. Subsequent accounting requests may be subject to a reasonable cost-based fee.
- **Right to a paper copy of this notice.** You or your representatives have a right to a separate paper copy of this Notice at any time even if you or your representatives have received this Notice previously. To obtain a separate paper copy, please contact the Privacy Official in writing at P.O. Box 4860, Ocala, FL34478. The Notice of Privacy Practice is also posted on the HMC website [www.hospiceofmarion.com](http://www.hospiceofmarion.com)
- **Right to breach notification.** You have a right to be notified if a breach of your unsecured protected health information has occurred. Unauthorized disclosure of your health information is presumed to be a breach unless a risk assessment shows a low probability that the information was compromised.

#### **DUTIES OF HOSPICE OF MARION COUNTY**

HMC is required by law to maintain the privacy of your health information and to provide to you and your representative this Notice of its duties and privacy practices. HMC is required to abide by the terms of this Notice as may be amended from time to time. HMC reserves the right to change the terms of its Notice and to make the new Notice provisions effective for all health information that it maintains. If HMC changes its Notice, the HMC will provide a copy of the revised Notice to you or your appointed representative. You or your personal representatives have the right to express complaints to the HMC and to the Secretary of the U.S. Department of Health and Human Services if you or your representatives believe that your privacy rights have been violated. Any complaints to the HMC should be made in writing to the Privacy Official at P.O. Box 4860, Ocala, FL 34478. The HMC encourages you to express any concerns you may have regarding the privacy of your information. You will not be retaliated against in any way for filing a complaint.

#### **CONTACT PERSON**

HMC has designated the Privacy Official as its contact person for all issues regarding patient privacy and your rights under the Federal privacy standards. You may contact this person at P.O. Box 4860, Ocala, FL 34478 (352) 873-7400.

#### **EFFECTIVE DATE**

This Notice is effective January 2014.

If you have any questions regarding this notice, contact the privacy official at P.O. Box 4860, Ocala, FL 34478 (352) 873-7400.

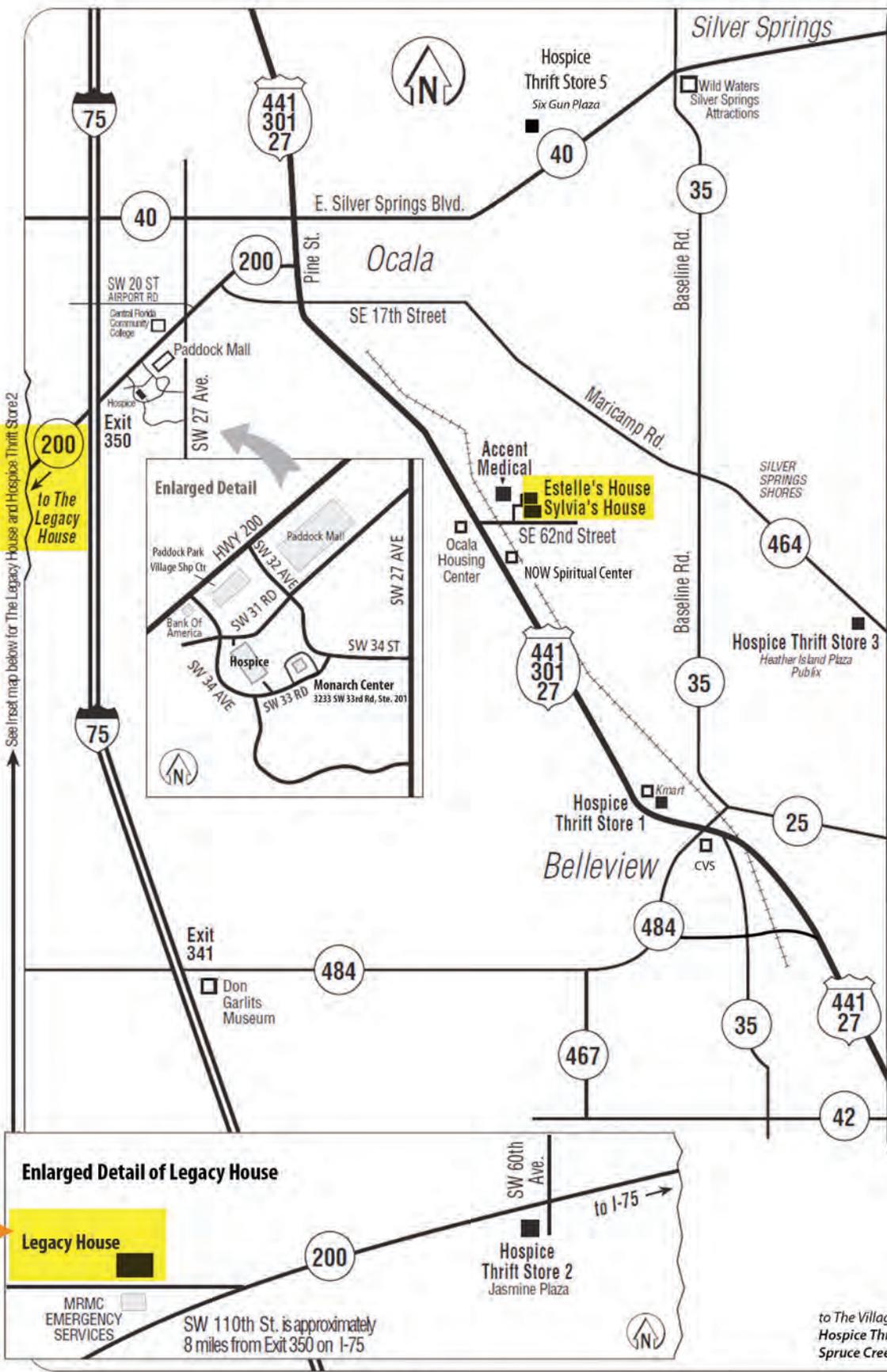
**HOSPICE**  
OF MARION COUNTY  
*Feel better. Live better.*

**The Elliott Center**  
**(352) 873-7400**  
3231 SW 34th Ave.  
Ocala, FL 34474  
**www.hospiceofmarion.com**  
**The Monarch Center**  
3233 SW 33rd Rd, Ste. 201  
(352) 873-7456

**Estelle's House**  
**(352) 629-4556**  
2897 SE 62nd St., Ocala, FL 34480  
**Sylvia's House**  
**(352) 629-1313**  
2895 SE 62nd St., Ocala, FL 34480  
**The Tuscany House**  
**(352) 307-3417**  
17395 SE 109th Terrace Rd.,  
Summerfield, FL 34491  
**The Legacy House**  
**(352) 291-5100**  
9505 SW 110th St., Ocala, FL 34481

**Thrift Store 1 (Bellevue)**  
**(352) 245-8175**  
10325 South Hwy 441, Bellevue  
**Thrift Store 2 (State Road 200)**  
**(352) 237-7707**  
6126 SW State Road 200, Ocala  
**Thrift Store 3 (Silver Springs Shores)**  
**(352) 680-9698**  
7578 SE Maricamp Rd., Ocala  
**Thrift Store 4 (The Villages)**  
**(352) 307-7555**  
17860 SE 109th Ave, Summerfield  
**Thrift Store 5 (Six Gun Plaza)**  
**(352) 236-5932**  
4901 E. Silver Springs Blvd Suite 603, Ocala

**- The Tuscany House**  
**- Summerfield Suites**  
SE 175th Pl.  
STONECREST  
to The Villages and  
Hospice Thrift Store 4  
Spruce Creek Terrace Shoppes



See inset map below for The Legacy House and Hospice Thrift Store 2

**200**  
to The Legacy House

**Enlarged Detail of Legacy House**

**Legacy House**

MRMC  
EMERGENCY  
SERVICES

SW 110th St. is approximately  
8 miles from Exit 350 on I-75

3 separate legal companies  
working together to provide  
exceptional quality and  
compassionate care.

**AFFILIATED COMPANIES**

**Center for Comprehensive Palliative Care**  
**(352) 291-5881**  
3231 SW 34th Ave.  
Ocala, FL 34474

**Accent Medical**  
**(352) 622-7260**  
2891 SE 62nd St.  
Ocala, FL 34480

**SummerField Suites Assisted Living**  
**(352) 307-0222**  
17421 SE 109th Terrace Rd.  
Summerfield, FL 34491  
**& Memory Care**