



# PATIENT & FAMILY CARE GUIDE



## Care Guide for Patients and Families

### OUR LEGACY AND PROMISE TO YOU

For over 35 years, Hospice of Dayton and Hospice of Butler & Warren Counties have served the needs of our local communities by providing the very best end-of-life care, support and comfort for any patient or family that needs it.

Our promise is to celebrate the lives of those we have the privilege of serving by honoring memories, sharing stories and cherishing moments in time. Our commitment is to provide superior care and innovative services that meet the physical, emotional, and spiritual needs of our patients and their families, with an emphasis on compassion, dignity, privacy, and respect when it matters the most.

We provide compassionate care and support to our patients and their families in our Hospice Houses, in their homes, in hospitals, and in extended care and assisted living facilities.

### YOUR GUIDE TO HOSPICE OF DAYTON CARE & SERVICES

While planning the contents of this guide, our goal was to ensure that you receive a convenient reference for everything related to our end-of-life care and services. We understand that as a patient or caregiver, you need confidence, peace of mind, and comfort during this time. Our foremost goal is to provide you support and comfort, and we hope this guide will assist in the process.

As you read on, you'll find quick reference material, checklists, medical guides, financial information, legal considerations, a section for note taking and much more. If you have questions that reach beyond the scope of this guide, please contact a member of your Hospice Quality of Life Team. You'll find the numbers you need in the Quick Reference section. Remember, we are here for you.



Kent Anderson | CEO, Hospice of Dayton





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# A. CONTACTING YOUR CARE TEAM





Immediate response to any question is available by calling us at:

***937-258-4989 or 877-445-5086***

## We're Always Here for You

If you experience any of the following, please call us:

- Any time you have questions regarding your care, or services or you have an immediate need
- If you need to report a change in condition, such as acute pain, discomfort or breathing problems
- Any time you need emergency assistance – please call us before you call 911
- If you fall
- If you notice a new or uncomfortable symptom
- Whenever you wish to speak with a member of our staff
- If you have questions about medical needs or medical supplies, such as the hospital bed, oxygen tank, etc.
- If you have safety questions or concerns
- If you have a family caregiver issue, such as if the family caregiver is ill or unavailable to provide care
- If you have questions about transportation

We are always available for you if you have any questions.

## My Quality of Life Team

### NURSE/CARE MANAGER(S)

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

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

### PERSONAL CARE SPECIALIST(S)

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

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

### SPIRITUAL COUNSELOR(S)

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

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

### PATIENT & FAMILY SUPPORT

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

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

## SOCIAL WORKER(S)

Name:

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Name:

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## OTHER CARE TEAM MEMBERS

Name:

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Name:

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Name:

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Name:

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Immediate response to any question is available by calling us at:

***937-258-4989 or 877-445-5086***



# B. QUESTIONS AND ANSWERS



## Questions & Answers

We have provided this section as a convenient way to capture any questions you may have and allow your Quality of Life Team to respond with answers. This section will help keep this information readily available if you need it for future reference.

QUESTION:

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# C. PATIENT & FAMILY SUPPORT





## Your Quality of Life Team

As your personal Quality of Life Team, we look forward to meeting your physical, emotional, and spiritual needs through our expertise and commitment to you. Quality of Life Team members wear name badges so they can be recognized easily by patients and family caregivers as part of the team.

### *Role of Hospice Team*

In addition to providing care and comfort, your Quality of Life Team:

- Provides family support in identifying physical, social, emotional, financial and spiritual needs, with referrals to other community resources as necessary to meet those needs
- Educates family caregiver(s) in skills needed for effective care

### *Physician*

We work directly with your personal physician in the management of your care. Our nurse will notify your doctor about changes in your needs or status. If you require inpatient care and are admitted to one of our Hospice Houses, your care will be provided by our medical Care team consisting of Physicians and Advanced Practice Nurses specializing in hospice and palliative care. Our full-time Medical Directors are experts in managing symptoms and work to develop personalized solutions for each and every circumstance. They are certified in hospice and palliative medicine and are available to work with your personal physician at any time.

### *Care Managers*

Nurses serve as care managers. The frequency of visits will depend upon your needs. Your nurse will assess your physical status at each visit and will provide education to you and your family caregiver about how to best provide your care, how to control symptoms, and what to expect next.

### *Personal Care Specialist*

Our Personal Care Specialists help patients with personal care such as dressing, bathing, eating, etc. The number and frequency of visits depend upon the individual needs of patients. Their support also includes light housework and patient meal preparation. Personal Care Specialist support is available in nursing homes and assisted living environments as well as in private residences.

### *Spiritual Care*

We embrace the role of your personal clergy as spiritual counsel and welcome him or her as a member of our Hospice team. We are an ecumenical organization and our chaplains support all religious and spiritual backgrounds; they are available 24 hours a 7 days a week for spiritual support and comfort.

### *Family Support & Bereavement Care Services*

Our Social Workers offer support as you face the challenges of change, decision-making and loss. Your social worker can help with the emotional impact of grief and bereavement as well as assist you with practical concerns such as insurance, veteran's benefits and connections to helpful community resources.



### *Therapists*

Innovative treatments are available through physical, occupational, skin, pet, music, massage and art therapies.

### *Pharmacist*

Your community pharmacist and Hospice pharmacist will provide written information regarding your medications. Our Hospice pharmacists review medication records to ensure the compatibility of medications and optimal use.

### *Volunteers*

Volunteers are available to provide a variety of services to support patients and families including:

- Caregiver relief
- Animal assisted therapy
- Patient visits
- Transportation/deliveries
- Hair cuts
- Life Celebration video recording

All of our volunteers receive special training and complete background checks to assure their integrity and reliability.

### *Around-the-Clock Services to Support You*

We try to help you anticipate problems before they occur or become a concern. Our nurses, social workers, chaplains, and physicians are always available. If an emergency occurs, please call **937-258-4989** or **1-877-445-5086**. A nurse is always available to assist you, including situations in which a medication needs to be evaluated at night, on a weekend, or during a holiday.

## Our Services & Support

We are passionate about patient care and all of the services we are privileged to provide you. We provide comfort, care, and support to patients in their home, in extended and assisted living facilities, in hospitals, and in our Hospice Houses. We offer patients, families and their caregivers compassion, peace of mind and comfort during difficult times.

### *Hospice Care at Home*

Many patients receive care in the comfort of their own home. We offer education and support to family caregivers so that they may gain peace of mind and full confidence while embracing life's journey with their loved one at home.

### *Crisis Hospice Care*

If a patient enters a period of crisis in their home setting, nursing care can be provided on a continuous basis for a period of eight to 24 hours. We provide short-term continuous care management of acute medical symptoms to assure patient care and comfort.

### *Hospice Houses*

Patient care is also provided in our Hospice House in Dayton, at 324 Wilmington Avenue, and Lorelei's Place Hospice House serving Butler and Warren counties, at 5940 Long Meadow Drive in Franklin, Ohio.

### *Our Hospice Houses provide:*

Skilled medical and nursing care to improve patient comfort and provide peace of mind for both the patient and family caregiver. This level of care is for symptom management and care needs. Patients may return to their residence once symptoms are relieved. In-patient care for management of symptoms is also available at contracted area hospitals.



### *Respite care:*

Respite care is short-term in-patient care that can be provided to a patient when it is necessary to relieve family caregivers who are providing care. Respite care is available for up to five days at a time and is offered in our Hospice Houses or an extended care facility.

### *Hospice Care in Extended Care and Assisted Living Settings*

Hospice patients who reside in a nursing home or assisted-living facility can receive care in their residential environment, benefiting from the combined expertise of the facility's staff and the Hospice team. We partner with an extensive number of area extended care facilities. Residents and their families are supported with coordinated physical, emotional and spiritual care.

Members of the Hospice staff coordinate with long-term nursing home staff to provide exceptional, flexible and personalized support for each patient. This care option enhances quality of life, allows for superior pain and symptom management, and increases peace of mind for patients and family. Additionally, residents and family caregivers receive seamless, superior care and support on every level. The patient's medical care will continue to be provided by the attending physician at the nursing facility. Our Medical Directors are available for consultation.



## Grief & Bereavement

The grief experience can impact people at various levels – physically, psychologically, spiritually, socially and emotionally. Sadness and sorrow are normal reactions. It's important to recognize that grief, as painful as it is, is a necessary part of the process.

Patients and those who are emotionally linked to them commonly experience anticipatory grief. It involves acknowledging the many losses that will occur as health and vitality slip away. Grieving also reminds us of other losses experienced previously in life.

### **It may help to know that it is not uncommon for patients to feel:**

- Sadness and grief
- Frustration and irritation toward family caregivers who may not always be able to meet their needs
- Guilt about not being able to care for themselves
- Anger about being sick and having to depend on others
- Resentment, impatience, fear and anxiety about their illness
- Worry about the pain their loved ones are experiencing
- Concern about the well-being of those who will survive them

### **Normal feelings for family caregivers often include:**

- Guilt about the ability to meet the needs of the patient
- Shame about feelings of resentment, frustration or fear
- Fear of not being able to “do enough”
- Anger about the role of family caregiver
- Fear about the future
- Sadness

Some symptoms are normal to the grieving process and are commonly experienced. Some of the same symptoms are also common to depression. It's important to know that if such symptoms are experienced in combination, it may indicate a more serious problem.

## GRIEF

## DEPRESSION

Loss of energy or feeling tired frequently	Severe exhaustion not relieved by rest or sleep
Sleeping too little or too much	Wishing you would never wake up
Troublesome thoughts	Thoughts of death or suicide
Increase or decrease in appetite or weight	Compulsive eating with significant weight gain or severe loss of appetite with significant weight loss
Trouble thinking and remembering	Overwhelming feelings of guilt and worthlessness
Restless feelings and inability to sit still	Loss of interest in people/things one enjoys. Feelings of emptiness
Feeling nervous and edgy	Feeling very anxious and worried; high levels of fear
Tearfulness	Feelings of overwhelming hopelessness or helplessness
Ability to feel pleasure and recognize humor remains	Loss of sense of humor; inability to experience pleasure; emotional numbness
Preoccupation with the loss	Preoccupation with self rather than the loss
Sexual difficulties	Loss of sex drive
Spiritual distress/questioning; anger with God	Feelings of despair/abandonment

Although physical complaints such as headaches, body aches, digestive problems and other health concerns are often part of the grief process, we encourage you to follow up with a physician to rule out other causes. Patients and family members are encouraged to express their feelings, questions and concerns with the care manager, patient and family support social worker or chaplains.

## Grief Counseling

### *Pathways of Hope*

Pathways of Hope is available to support individuals and groups with counseling services, free of charge and provided by licensed staff. Bereavement counseling through Pathways of Hope is available to those currently enrolled in hospice care (including the patient), as well as those that have previously been a part of the program and have already lost a loved one, and to anyone else in the community who has experienced the loss of a loved one. Grief education groups as well as grief support groups are open to anyone experiencing loss, as well as groups designed to meet specific types of losses such as death of an adult child or spouse. Your family support social worker can provide information on the groups. Grief support services are available through Pathways of Hope at any time.

### *Contacting Pathways of Hope:*

- Call 937-258-4991 Mondays through Fridays between 8:30 am and 5:00 pm
- Call 937-256-4490 or 1-800-653-4490 24 hours a day, 7 days a week
- In Butler and Warren Counties, call 513-422-0300 or 1-800-653-4490

## Patient Care & Safety

### PATIENT & CAREGIVER SAFETY

We realize that safety is of primary importance for patients and family caregivers. We will check your home for safety concerns and offer suggestions if we find situations that may put you at risk for injury or infection.

If you have a safety concern, you can call for assistance at **937-258-4989** or **877-445-5086**.

### GENERAL SAFETY

#### *Rugs, runners and mats*

- Remove or secure loose rugs, runners and mats with double-sided tape or rubber matting
- Replace or repair torn or frayed rugs to prevent tripping
- Tack carpets down

#### *Telephone*

- Keep a phone near the bed for use without standing or walking
- Put emergency phone numbers in an easy-to-find place near the phone

## PREVENTING INFECTION

As an illness progresses, patients become more susceptible to infection. Standard precautions will help protect both patients and family caregivers. Precautions begin by assuming that all blood and body fluids can spread infection.

### *General Guidelines*

Hand washing is the single most important thing you can do to prevent the spread of infection. When washing your hands, scrub between fingers, around fingernails, the backs of hands and wrists. Make sure family caregivers wash their hands before and after providing direct patient care, before food preparation, before eating or feeding the patient, and after toileting or assisting the patient with toileting.

### *Wear Gloves*

Disposable gloves should be worn whenever a family caregiver has direct contact with body fluids, such as mucous, vomit, blood, urine or stool, and when handling soiled items, bedpans, commodes or soiled pads from the patient. Remember to wash your hands before putting on gloves and after removing them.

### *Dispose of Waste Safely*

Dispose of all used needles in a puncture-proof, hard plastic or metal container with a screw-on, tightly secured lid (e.g., a bleach bottle). Your Hospice nurse can provide you with a container for the disposal of needles and more information on how to discard needles.

### *Cover Your Cough*

Always cover your mouth and nose with a tissue when you cough or sneeze. If you do not have a tissue, sneeze or cough into your upper sleeve or elbow, not your hands. If you are ill you may be asked to wear a facemask to protect others from infection.

## PATIENT MOBILITY & PREVENTING INJURY

Your Quality of Life Team can provide training in any of the following areas:

### *Moving the Patient*

Patient position should be changed every few hours or as needed. Always explain to the patient what you are going to do before taking action. When moving a patient, encourage the patient to help as much as possible. If a patient is unable to assist in moving, family caregivers need to minimize the strain on them to prevent injury. Always proceed by taking the following precautions:

- Be aware of catheters, tubing, or dressings before moving
- Loosen blankets and remove pillows
- If the patient has an electric bed, lower the head of the bed and raise the bed to waist level
- Keeping your back straight, bend at your knees and use the strength of your legs to assist with moving the patient
- Stand as close as possible to the patient, keeping feet spread for a firm balance
- Use your legs instead of your back when lifting or moving the patient
- If transferring the patient from bed to chair, turn with your entire body. Do not twist your upper and lower body separately
- If capable, have the patient use side rails to help with turns

### *Moving a patient who cannot help*

Your nurse or Personal Care Specialist will demonstrate the procedures:

- Two people and a lift sheet are required. A lift sheet can be a folded sheet
- Place the sheet under the patient, from the shoulders down to the thigh area

- Lower the head of the patient's bed and remove any pillows. Then raise the entire bed to the waist level of the lifter. If the patient begins to have difficulty breathing when you lower the head of the bed, raise it back up
- Cross the patient's arms over the chest and bend the patient's knees, if possible
- Say "1-2-3-Go," then pull and lift toward the head of the bed with the lift sheet

### *Moving a patient by yourself*

- Pull the patient toward you when rolling him or her from side to side
- If the patient can tolerate the head of the bed in a lowered position, lower the head of the bed and remove pillows; and, slightly raise the foot of the bed
- If the lift sheet is tucked, loosen it
- To pull the patient up in bed, stand at the head of the bed and grasp the lift sheet as close to the patient's shoulders as possible, one hand on each side
- Slide and pull the patient upward

### *Sitting a patient up on the side of the bed*

- Do not twist at your waist. Always remember to turn your entire body
- Ask the patient (if able) to help by pulling up on the side rail
- Roll the patient onto his or her side
- Lower legs gently off the side of the bed
- Use one arm to support the neck and shoulders, the other to support under legs
- Gently raise the patient to a sitting position



*Moving a patient from bed to chair or bedside commode, etc.*

- Place the bedside commode right next to the bed and be sure the brakes are lowered into a locked position
- Stand directly in front of the patient as he or she sits on the side of the bed
- Spread your feet the width of your shoulders
- Position your knees on either side of the patient's knees, in a straddle position
- Keeping your back straight, bend slightly at the knees
- Place your arms around the patient's upper chest, beneath the armpits (in a hug-like position)
- Straighten your legs to lift the patient
- Do not twist at the waist; turn your entire body when moving the patient
- Slowly lower the patient to the chair by bending your knees



## PREVENTING PATIENT FALLS

Your nurse will work with you to develop a plan to prevent falls and discuss what to do if a fall occurs. Patients at risk of falling who live alone may need to wear a small alarm/monitor device. A sign may also be posted to alert all caregivers of the risk for falls.

*A patient may be more likely to fall and be injured because of:*

- Urgency to go to the bathroom
- Weakness due to illness
- Problems with balance
- Poor vision or poor lighting
- Tingling or numbness in feet or hands
- Drowsiness (caused by some medications)
- Environmental hazards, such as: throw rugs or slippery floors, telephone or electric cords, and oxygen tubing
- Changes in medication, particularly those for pain or high blood pressure
- Raised bed rails
- The telephone being out of reach
- Cluttered walkways, uneven flooring, doorways or wheeled furniture (such as carts, tables, chairs, etc.)
- Loose-fitting shoes, slippers or clothing that might “catch” on furniture or rails

*To prevent falls, patients should:*

- Sit upright and count to 10 before standing. Take it slow
- Use a cane or walker if prescribed to help you balance, or ask your family or professional caregiver for assistance if you feel unsteady
- Turn on the lights, use brighter light bulbs and wear your glasses
- Wear slippers that have “tread” on the soles and fit snugly

- Have throw rugs removed in all areas where you walk
- Clear walkways of clothing, books, papers and toys
- Add handrails in the bathroom
- Be careful on the stairs. Use the handrail or ask for help
- Keep your bed in the lowest position when getting up during rest
- Keep necessary items within easy reach
- Use a cordless telephone
- Coil and tape phone and electrical cords

### *What to do if you fall*

If there is no pain or bleeding and no obvious injury:

- If you feel able, get up with or without your caregiver's help
- If you can't get up and your family caregiver can't help you up, call someone on your fall-prevention plan, like a close neighbor or family member who lives nearby
- If there's no one available, call your nurse to help you
- Notify our Care Coordination Center of the fall at 937-258-4989 or 877-445-5086
- Talk with your nurse about obtaining a personal alarm

### *To prevent falls without using restraints*

- Place a mattress on the floor; if not using a hospital bed, use a low bed
- Provide a bell, intercom or other call system to allow the patient to easily call for help. A baby monitor permits family to move about and continue listening in another area of the house
- Keep things the patient may need close to the bedside, within easy reach
- Keep a night light on at night

Discuss patient alarms with your nurse, which can alert family caregivers when a patient is trying to get up.

### *Concerns about agitated or confused patients*

Family caregivers sometimes worry that a confused or agitated patient may unintentionally injure themselves because of their mental state. Talk with your nurse about options that will help keep your loved one safe.

If the patient is agitated:

- Use low room lighting, talk quietly and keep stimulation to a minimum
- Have someone in the room with the patient to calm and reassure them
- Never restrain a patient. Our professional staff members can provide you with multiple options to help care for your loved one
- Contact your primary nurse. Agitation may be caused by lack of oxygen, chemical imbalance or reaction to medicine. After 5pm on weekends, contact our Care Coordination Center for assistance at 937-258-4989 or 877-445-5086

## COMFORT MEASURES AND CLEANLINESS

### *Skin Care*

Basic skin care is very important during an illness. Regular hygiene, such as bathing or showers, use of shampoo and lotion for dry skin, should be maintained as long as the patient can do so without assistance. Contact your nurse if the patient is unable to bathe or provide personal skin care for him or herself. A member of your Quality of Life Team will come to assist.

Special emphasis on skin care may be needed if the patient is weak, not eating well or very tired. Sitting or lying in bed over an extended period of time places patients more at risk for skin problems. Skin breakdown and sores can result from prolonged pressure on boney areas. Buttocks, shoulders, heels, elbows and other such areas are the most likely spots for the development of sores. A very good preventative measure is to change position at least every two hours. Any changes in skin such as reddened areas or skin breakdowns should be reported to the Hospice nurse right away.

If the patient is receiving radiation therapy to reduce pain, do not apply any lotion within the marked radiation area on the skin.

The patient or family caregiver should check the skin regularly for reddened areas. Pay particular attention to sites with increased pressure, such as the buttocks, shoulders, heels and lower back.

### *Turning and Positioning:*

- Turn or change position every few hours, as tolerated
- Prop with soft pillows
- If sitting, shift weight frequently
- Pressure-relief devices and products are available

*The nurse can advise which method above is best suited to the patient's individual needs.*

### *Bathing the Patient*

Cleanliness helps prevent skin problems; so, bed-bound patients should be bathed regularly.

Things you will need for the bath include:

- A large bowl with warm water
- Mild soap (soaps with a high fat content, such as Tone or Dove, are best for moisturizing)
- Washcloths and towels
- Light bed cover to prevent chills

### *How to give a bed bath:*

- Prepare the room by checking for drafts and turning up the heat if necessary
- Protect the bed sheets from becoming damp by using towels or a lightweight cover

- To avoid chilling the patient, expose and bathe only a small area at a time. Gently wash the patient's skin in a small circular motion, rinse off all soap (or use rinseless soap) and pat dry. Begin by washing the patient's face, followed by chest, abdomen, arms, hands, legs, feet and back. Apply lotion
- After washing the back, change the water before washing the buttocks area. Daily washing of the genital area is especially important, since bacteria collect there. To prevent spreading bacteria from the rectal area, wash between the patient's legs from the front toward the back. Rinse well and dry gently with a towel. A skin-protecting lotion or water-repellent ointment should be applied to this area if control of stool or urine is a problem
- Waterproof underpads (not diapers or Attends) and lift sheet should be changed daily or more often. If possible, bed sheets should be changed once a week. This task usually requires two people. Flat bottom sheets are recommended, since they are easier to secure under the mattress. Help the patient to turn from side to side and change one side of the bed at a time. Your primary nurse can demonstrate how to make a bed with a person in it

*Things to remember about body cleansing:*

- Be sure to gather all necessary linens, bedclothes, towels, etc. before starting to bathe the patient
- If movement causes pain, give the patient pain medication about one hour before his or her bath
- Provide privacy during the bath. Close the door and drapes to reduce interruptions
- If the patient is in a hospital bed, raise the level of the bed to reduce the strain on the family caregiver's back
- Keep the patient's body covered with a light blanket or sheet during the bath to avoid chilling
- If the patient feels unable to tolerate a complete bath, try to wash the face, hands, back, underarms and genitals daily

- Do not use powders, except under the arms. Powder tends to cake in body creases. Instead, cornstarch can be sprinkled lightly between the patient and the linens. Brushing and styling the hair, as well as shaving, can also be done around bath time. For some patients, attention to usual personal habits will help lighten their spirits. If the patient tires easily, allow rest periods between tasks
- Keep dry, flaking skin lubricated with creams or over the counter lotions
- Skin-to-skin contact areas (between legs, under breasts or in folds of abdomen) can cause irritating wetness. Dry these areas thoroughly
- Report any reddened or irritated skin areas to the Hospice nurse immediately

### *Mouth Care*

The linings of the throat and mouth are sensitive and sometimes need special care. Regular cleaning of the mouth helps prevent sores and may improve the patient's appetite.

Items needed for mouth care include:

- Soft toothbrush or "toothette"
- Toothpaste
- Mouthwash (non-alcohol)
- Cool water
- Small bowl
- Dry cloth
- Moisturizer
- Towel



*Instructions for mouth care:*

Cleanse the mouth and teeth two times daily. The patient may prefer to do this him or herself. The patient should be in a half-sitting or sitting position to prevent choking. Place a dry cloth under the chin. Use either a toothette or soft toothbrush. Check the inside of the mouth for redness or white patches. If the throat is sore, report this to the nurse. Be sure to report any bleeding to the nurse.

**Wash your hands.** If the family caregiver is providing mouth care, he or she should make sure to wash his or her hands as well.

*Care of permanent teeth:*

- Brush upper and lower teeth with toothbrush and toothpaste. Place the brush as far back as possible without causing gagging and brush in a circular motion over biting surface and sides of teeth
- Rinse mouth
- Rinse with mouthwash if desired
- Apply cream or ointment to lips

*Denture care:*

- Remove dentures
- Brush upper and lower dentures or dental appliances, carefully protecting dentures or dental appliances in emesis basin or denture cup
- Rinse mouth
- Cleanse the patient's mouth and lips with a soft toothbrush, toothette or washcloth prior to replacing dentures

As the patient loses weight, dentures may not fit properly. A poor denture fit can result in mouth sores. If refitting the dentures by a dentist is not possible, leave the dentures out and continue to perform mouth care at least twice a day. Discuss poor fitting dentures with your nurse.





After finishing the patient's mouth care, apply a moisturizer to the lips and both corners of the mouth to prevent cracking. Reapply as needed.

### *Mouth Infections:*

Poor mouth care, some drugs and some treatments can all result in mouth infections. If the patient develops sore areas in the mouth, redness or white patches on the gums or on the tongue, report these to the nurse. In the event of a mouth infection:

- Maintain a bland diet. Avoid spicy or highly seasoned foods
- Limit the use of dentures until the infection is gone
- Avoid foods and liquids that are very hot or very cold
- Continue careful mouth care and cleaning after meals and at bedtime

### *Dry Mouth:*

- Encourage taking small sips of water at the bedside or sucking on candy, ice chips or popsicles
- Keep lips moist
- Use artificial saliva, as needed
- If the patient can tolerate it, sugarless gum/candy, chewable vitamin-C tablets or pineapple chunks can be used to stimulate saliva
- Continue to rinse the mouth with a baking-soda solution. Do not use mouthwash

## MEDICATION SAFETY

Medications come in different forms, including pills, liquids, inhalants, patches, suppositories and ointments. Your physician orders medications specifically for you. It is important that you take all medications, as ordered, and that you only take your medications. Medications can be essential to your comfort. There are some very important Do's and Don'ts regarding medications.

### *Do:*

- Tell your nurses and doctors about all prescribed, over-the-counter medications, vitamins or herbal treatments or supplements
- Tell your doctor or nurse about any allergies you have
- Read labels and follow all dosage instructions as closely as possible
- Take all oral (by mouth) medications with a full glass of water, if possible
- Shake all liquid medications well before measuring
- Follow your pharmacist's, physician's or nurse's instructions about the proper time to take medications (e.g., before or after meals, around the clock, etc.), avoiding certain foods or other dietary advice
- Keep a written record of all medications you take
- Be sure you have enough of each medication to get through weekends and holidays. Contact the nurse if you are running low (less than a two-day supply).
- Ask your nurse what to do with medications you are no longer taking
- Ask for clarification if you have any questions or think you may be having side effects or a drug reaction
- Store narcotics out of sight

***Keep all medications out of the reach of children.***



***Don't:***

- Change the dose or timing of any medication without your doctor's advice
- Remove labels or move medications to a different container unless instructed to do so by the nurse
- Take more or less medication, unless directed to do so
- Stop taking medications, unless directed to do so. Some medicines can cause severe side effects unless decreased slowly
- Take any medications in the dark
- Take other people's medications or share yours with them
- Drive or operate hazardous machinery if drowsy from medications
- Drink alcohol with most drugs
- Share information about your medications with people who do not require such information
- Crush your pills without first checking with your nurse

***Don't be afraid to ask questions.******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 or breaking any pills, since some pills cannot be crushed or broken
- When using liquid medicine, the patient's head should be slightly tilted upright and the medicine poured down the side of the mouth
- When administering medication under the tongue or between the cheek and gum, moisten the area with two to five drops of water and then place the pills in the area, as directed by your nurse

### *Giving Medications Rectally*

Patients having difficulty swallowing pills may need to take some medications rectally. Family caregiver assistance may be required.

Items needed for rectal administration of medications include:

- Gloves
- Water-soluble lubricating gel, such as K-Y Jelly

#### *Instructions:*

- The patient should empty his or her bowels, if possible. The insertion of the rectal medication may give the patient the desire to have a bowel movement
- Wash hands and put on gloves
- Remove any wrapper on a suppository. At the direction of your nurse, a pill or capsule may be put into the rectum either as is or in a gelatin capsule
- Put a large dab of lubricating gel on the suppository, pill or capsule
- If possible, the patient should lie on the left side, with knees pulled up and toward their chest, during insertion
- The patient should take a few deep breaths and try to relax as the medication is inserted with a finger of the gloved hand
- Push the medication in as far as it will go
- The patient should try to hold the medication without having a bowel movement for at least 20 minutes, so medication can be absorbed
- Remove gloves and wash hands

### *Drug Disposal*

When medications are no longer needed or in use by the patient, we are obligated to assure safe and proper disposal. Prescription drugs may not be removed from a patient's home by a member of the Hospice staff.

Because Federal law prohibits the transfer of prescription medications to any person other than the person for whom it was prescribed, Hospice of Dayton is not permitted to accept any donated drugs, including controlled substances.

Directions for safe disposal of medications are detailed below. However, if you have any questions or concerns concerning drug disposal, please ask your nurse case manager or call 937-256-4490.

*Instructions:*

- Remove and destroy all identifying personal information from all medication containers before disposing of them.
- Pour unused or expired solid medication into a sealable plastic bag
- Crush the medication through the plastic bag
- Add unused or expired liquid medications
- Add a small amount of water to help dissolve solid medications
- Add kitty litter, sawdust, vinegar, or used coffee grounds to the plastic bag
- Seal the bag, and gently mix the contents together
- Toss the bag into the trash

***Ohio law requires that some drugs be disposed of by being flushed down the toilet. However, unless specifically instructed, medications should not be disposed of by flushing them down the toilet. Call Hospice of Dayton at 937-256-4490, or your local pharmacy, to determine if medications should be flushed. Gloves should be worn to discard all medications.***

*Other recommended disposal methods:* The DEA routinely organizes National Drug Take Back Collection Days. Check out <http://www.justice.gov/dea/> for upcoming dates and locations. Local pharmacies often organize Drug Take Back events. Please check with your local pharmacy.

## SYMPTOM MANAGEMENT

### *Weakness*

Weakness is a common symptom due to disease, poor nutrition, anemia, depression or the side effects of treatment.

Patients may feel symptoms like:

- Little or no energy
- Increased sleepiness
- Decreased interest in activities
- Episodes of falling (with or without injury)

When a patient is weak, it's important to:

- Conserve energy by taking time to rest frequently
- Prioritize activities
- Pace activities, including bathing, dressing, eating, etc.
- Have someone assist with walking, to prevent falls
- Stay in bed when very weak, to prevent falls

### *Shortness of Breath*

Lung disease, pneumonia, fluid in the lungs or anxiety can make it difficult to breathe easily. The patient may complain of shortness of breath or display such symptoms as chest pain, wheezing, a pale or blue skin color, sweating, a rapid pulse or fast breathing rate. Activities should be paced during the day to permit rest periods. Whenever possible, the patient should sit while performing daily activities such as brushing teeth, showering, shaving and talking on the phone. If shortness of breath occurs during an activity, it may be easy to relieve by simply resting.

*If breathing problems occur:*

- If possible, the family caregiver should stay with the patient and remain calm and reassuring
- If oxygen is being used, make sure that the equipment is running properly and that there is no kink or bend in the tubing that might cause the oxygen to be cut off
- Raise the head of the bed or prop the patient up with pillows
- Administer medications, as directed by the doctor
- Practice slow, deep breathing with the patient routinely, so this type of breathing comes more easily during periods of shortness of breath
- Try cooling the room down with a fan and air circulation, such as an open window
- Instruct the patient to inhale through the nose and breathe out through pursed lips, as if whistling. This helps prolong the “breathing out” phase and relax airways. Stay with the patient, performing this breathing pattern with them
- Encourage relaxation of the shoulders, back and arms. Use touch and massage, if the patient agrees this will help

*Oxygen Use:*

Some patients will need oxygen. Shortness of breath that does not go away easily with the previous suggestions should be brought to the attention of the nurse. The nurse and physician will decide whether oxygen is necessary.

Oxygen is sometimes supplied with small green tanks that can be turned on for occasional use, as needed. If the patient needs oxygen most of the time, the nurse will suggest an oxygen concentrator. An oxygen concentrator is an electrical device that purifies oxygen from room air. The concentrator gives the patient nearly pure oxygen through a nose tube or mask.

Liquid oxygen is oxygen that is cooled to -29 degrees Fahrenheit. When it is warmed, it turns into a gas. Liquid oxygen is contained in large tanks under low pressure and is safe.

The company providing the oxygen will demonstrate how to use the equipment. The Hospice nurse can also help, if you have questions or concerns about the use of the equipment.

Be sure to check that the oxygen flow is set at the prescribed number. ***Do not increase the flow without checking with the nurse first.*** If using nasal tubing, place the nose prongs in the nose, making sure the prongs are curved upwards. Bring the tubing around each ear to help hold the prongs in place. If the tubing makes the ear area sore, pad the tubing with cotton.

The tubing for oxygen can be cleaned with a damp cloth as needed. Replace tubing or face mask every two weeks. If using a concentrator, completely clean the filter every week. Replace the filter after it is absolutely dry.

*Helpful hints:*

- ***Do not smoke or light a match in the same room with running oxygen***
- The nose may dry out. Use a water-based lubricant such as K-Y Jelly, in the nose. ***Do not*** use Vaseline or other petroleum-based products
- Place cotton behind the ears, where the oxygen tubing rests. This will decrease the pressure and irritation
- Keep the oxygen concentrator away from walls and drapes
- Keep the oxygen tubing away from walkways
- Hold the oxygen tubing to the side as the patient walks
- Maintain oxygen tanks in an upright position, placed in metal stands
- Store oxygen tanks in a safe, dry area
- If the oxygen concentrator is not working, check the cap on the water bottle



### *Bleeding*

- Avoid using sharp objects
- Use an electric shaver
- Use a soft toothbrush, a sponge toothette or a washcloth to clean teeth.  
Floss carefully
- Give rectal medicine gently and with a lot of water-soluble lubricant
- Encourage the patient to practice gentle nose blowing
- Instruct the patient to always wear slippers or shoes when out of bed

### *Report any of the following to the Hospice nurse:*

- Blood in urine, stool, sputum (phlegm) or vomit
- Black stool (that looks like tar)
- Vomit that is dark brown or bright red
- Bloody nose (several or one that is not easy to control)
- Multiple bruises
- Many small, reddish-purple dots under the skin
- Confusion or increased sleepiness

***If bleeding occurs, apply pressure by using a towel and holding it where the patient is bleeding; then call our Care Coordination Center at 937-258-4989 or 877-445-5086.***

### *Swelling and Fluid Retention*

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

- A weakened heart
- Less protein in the diet
- Less moving around

#### *Steps that can be taken to help relieve fluid buildup include:*

- Elevating the areas that are swollen above the heart, if possible (if not, elevating as high as possible)
- Avoiding tight-fitting clothing, belts, socks, rings or shoes
- Avoiding salt (which involves checking foods for high salt and/or sodium content)
- A “water pill” (diuretic), prescribed by a physician, to help eliminate excess water through the kidneys
- Moving around, as the patient is able
- Exercises performed by the family caregiver to help with patient movement, if the patient is unable to get out of bed (the nurse can instruct the family caregiver)

### *Seizures*

- Stay calm
- Protect the patient from injury by:
  - Easing the patient to the floor or bed, if the patient is standing
  - Padding the bedrails
  - Removing any sharp or hard objects near the patient

- Help the patient with breathing by:
  - Turning the head to the side if secretions (phlegm) are present
  - Loosening tight clothing, such as belts or ties
  - Placing something soft, like a pillow, under the patient's head
- Do not force anything between the teeth
- Do not put your fingers in the patient's mouth
- Do not interfere with the patient's movements, unless it is absolutely necessary for safety
- Allow the patient to rest after the seizure is over
- Call us if:
  - Seizure is unusual for the patient
  - Seizure lasts longer than a few minutes
  - Injury occurs as a result of the seizure
  - You have any other questions or concerns

### *Nausea and Vomiting*

Nausea and vomiting are common problems and can be the result of:

- Movement
- Treatment procedures
- Medicine
- Constipation
- The illness
- Infection
- Pain
- Anxiety

*Report any of the following to your nurse:*

- Any abdominal bloating that is relieved by vomiting
- Any nausea you believe might be the result of medication or a change in medication

*Nausea and vomiting can be eased by:*

- Taking laxatives, as directed
- Getting a lot of rest
- Using anti-nausea medicine, as prescribed by the doctor
- Avoiding strong smells
- Slowly sipping ginger ale or peppermint tea

*Treatment for vomiting:*

- Do not allow the patient to eat or drink for two to four hours after vomiting. Instead, encourage rest
- After the four-hour point, only if the vomiting has stopped, start with ice chips. Allow the patient around two tablespoons of chips every 15 to 20 minutes. Popsicles or other flavored ice products are also fine
- If vomiting resumes, call us
- If the patient is able to take ice without vomiting for another two to four hours, then start with ginger ale-type products, broth, Gatorade or JELL-O
- Continue clear fluids for 24 hours
- After 24 hours of clear liquids, try adding dry toast, crackers or dry cereal
- If the vomiting resumes, call your nurse. Stop all fluids and food
- Call your nurse immediately if the contents of the vomit are bright red or dark brown

## *Constipation*

Constipation means a change in the normal bowel movements, where bowel movements are smaller, drier, harder or more difficult to pass.

The best way to treat constipation is to prevent it. Your nurse will establish a bowel regimen right for the patient. Pain medications almost inevitably slow the bowels and can cause hard, dry stools. If the patient is on pain medications a stool softener should be administered daily, and patients should drink plenty of water (eight glasses per day). If pain medication is increased, the use of a stool softener may also need to be increased. A number of products are available over-the-counter that can help. Your doctor or nurse will assist in selecting the right treatment. Any time a remedy has been attempted and the patient does not have a bowel movement after three days, it's important to report this to your nurse.

### *Causes of constipation include:*

- Decreased activity
- Decreased food and/or fluid intake
- Disease process
- Some medications, especially narcotics

### *If possible, try:*

- Warm prune juice or other fruit juices
- Increasing water intake
- Increasing activity
- Fresh fruit with skins
- Fresh vegetables (especially raw, green leafy vegetables)
- Whole-wheat or bran cereals and breads

## *Diarrhea*

Diarrhea is frequent, liquid bowel movements with or without discomfort.

### *Common causes of diarrhea are:*

- The flow of liquid around a blockage of stool in the rectum (an impaction)
- Medication or laxatives
- Infection
- Supplemental feedings
- Tumor growth
- Side effects from chemotherapy or radiation (may last several days)

### *Treatment for diarrhea:*

- Give the patient clear liquids, such as broth, ginger ale, JELL-O, and water. Don't allow him or her to stop taking fluids
- Give the patient foods high in protein and low in fiber, such as: cottage cheese, baked potatoes, boiled white rice, cooked cereal, bananas, pasta, white toast and applesauce, as tolerated
- Add nutmeg to food to slow down the movement of stool in the intestine
- Encourage rest
- Clean the rectal area with mild soap and warm water after each bowel movement. Rinse well and dry. Apply a water-repellent ointment to the area, such as a vitamin-D ointment or Desitin
- Try a warm tub bath, to help relieve the discomfort of rectal irritation

If diarrhea lasts more than 48 hours, the patient should drink only liquids until the diarrhea subsides. In addition, the patient ***should not***:

- Drink caffeinated or alcoholic beverages
- Consume milk or milk products
- Drink very hot or very cold liquids
- Use tobacco products

*Contact your nurse if:*

- The patient has more than six to eight bowel movements a day for more than two days
- There is blood in the stool
- Diarrhea causes significant cramping
- Patient has a fever above 101 degrees that does not respond to medication such as acetaminophen (Tylenol) or ibuprofen (Advil)
- Patient has been constipated and begins passing small amounts of liquid from the rectum
- Having a bowel movement does not relieve bloating and discomfort

## CATHETER CARE

During the illness, the patient may become weak, lose control or lose the feeling of when it is time to empty the bladder. If a urinary catheter becomes necessary, your nurse will place a catheter and coach the family caregiver in catheter care and maintenance.

A urinary catheter is a tube with an inflatable balloon at the end. The nurse or doctor will insert the tube into the bladder; once the tube has reached the bladder; the tiny balloon will be blown up, using a small amount of water. This balloon keeps the tube from falling back out. The nurse will connect the tube with a drainage bag. Urine will be seen in the tube as it drains to the bag.

*How to take care of the tube and drainage bag:*

- Observe the tube and bag to see if urine drains into the bag. If you do not see any urine for eight hours, call your nurse. Encourage fluids if the patient is able to drink
- Check the tubing to ensure that it is clear of kinks or bends and is connected to the bag. Keep the bag below the level of the bladder
- Wash hands before and after handling the tubing or bag. Use gloves when cleaning, changing or emptying bag
- Empty urine into an unfilled plastic milk or juice bottle. Clean this bottle in between each use
- Empty the drainage bag one or two times each day, more often if it becomes full
- Change the drainage bag every week. The nurse will teach you how to do this
- If the patient is active, watch to make sure the catheter isn't pulled out with movement. The caregiver may need to assist the patient with the tubing and bag. Your nurse can demonstrate how to secure the catheter

*How to clean the tubing:*

Items you will need:

- A basin
- Mild soap
- Several clean washcloths
- Gloves
- A clean towel



*Instructions:*

- After washing hands and putting on gloves, place the towel under the tubing to protect the patient
- With a wet, soapy washcloth, clean the area where the catheter enters the body. Wash gently, changing the part of the washcloth that is touching the body as you wash around the tube. Rinse this area
- If the patient is an uncircumcised male, gently pull back the foreskin before cleaning and replace the foreskin after cleaning. With a clean washcloth, wash the tubing, moving the cloth away from the body — never toward the body. Do not scrub
- When finished, clean up the basin and the washcloths. Make sure the patient is dry and comfortable. Then remove the gloves and wash hands

*Helpful hints:*

- If the patient is pulling the catheter, put on an adult diaper
- Do not allow the catheter tubing to be under a leg. Lay the tubing over the leg
- As the patient is turned from side to side, move the drainage bag from side to side
- If the patient is still up and walking around, the nurse can provide a leg bag for convenience
- Patients who are able to drink should consume 8–12 glasses of juice, broth, water, etc. per day



## NUTRITION

Food and drink play a significant role in our lives. Each of us can remember life events centered around food. Parents show responsibility and care as they feed a baby. Not offering food or drink is considered rude in many cultures. Not accepting the offered food and drink can sometimes be considered insulting. During the course of treatment for an illness, nutrition can become a major focus. Seeing a patient eat and drink less and less can make the family caregiver feel like the patient is rejecting efforts to provide care.

It is normal for terminally ill patients to eat and drink very little. Most terminally ill patients do not benefit from artificial fluids or foods. These measures can cause nausea, vomiting, increased congestion, pain and many other problems.

It is important to remember that it is normal for the patient's appetite to diminish as the disease progresses.

The patient must always be in control of what and how much to eat.

### *Some meal suggestions:*

- Do not force the patient to eat or drink
- Notice what time of day the patient has more energy and make that a mealtime. Many patients do well at breakfast, with less appetite as the day goes on
- Small meals, using smaller dishes, will be less overwhelming for the patient
- Give the patient choices, such as a bowl of pudding or ice cream
- Increase the calories of foods with cream, butter, cheese, powdered milk added to whole milk and powdered, high-protein supplements
- Leave high-calorie snacks within reach of the patient
- Eating can be tiring. Allow the patient to rest before and after each meal

- Make the eating experience quiet and pleasant
- Candles, flowers, soft music and good conversation all help
- Use an instant breakfast for anytime. Add ice cream and whole milk
- Add a bedtime snack, such as hot chocolate and toast
- Practice regular mouth care. A pleasant-tasting mouth will improve the taste of food
- If dentures do not fit, speak with a dentist for suggestions
- Give food a chance. What sounded unappealing today may sound fine tomorrow
- Many patients lose their taste for coffee, tea, fried foods and alcohol. Common acceptable foods are pasta, milk products, breads, custards, fruit and soups
- If nausea is a problem, use small portions, salty (not sweet) dry foods like toast, ginger ale and clear liquids if the nausea continues. You may also wish to speak with your nurse about a medicine that will help control the nausea before eating
- If swallowing is difficult, puree foods in a blender and add gravies, sauces or milk
- If the patient has mouth sores, use soft food that is neither hot nor cold. Stay away from salty foods and liquids containing alcohol. Notify your nurse so he or she can assess where a mouth infection is causing the problem
- Constipation may contribute to nausea and lack of appetite. Talk to the nurse about this problem and refer to the section on bowel care in this guide

It is important for the patient to take the lead. His or her body knows best. The kindest thing we can do is not shame the patient for not eating. There are much more important things to share at this time. Respecting the choice that the patient has made can demonstrate our love.

Frequent mouth care, small sips of fluid, ointment to the lips and light skin massage with lotion are all ways to support the patient at this stage.

### *Nutritional Boosts*

Patients who still have an appetite may have difficulty eating enough food to give their bodies the amount of calories needed to keep the energy levels high. Patients can boost the amount of calories taken in without eating higher quantities of food. Drinking commercially made nutritional-supplement foods (Carnation Instant Breakfast, Ensure, etc.) is a good way to up caloric intake. These drinks come in a variety of flavors and vary in price.

Some people do not like the taste of commercial supplements or find they are too expensive. There are other ways of adding calories and boosting energy using commonly available ingredients.

### *Fortified-food Suggestions*

- **Fortified milk:** Add one cup powdered milk to one-quart whole milk. Use in milkshakes, puddings, sauces, etc.
- **Instant breakfast:** Make with fortified milk. Add ice cream or whipped cream to it
- **Instant pudding:** Add whipped cream or use pudding as a thickener in milk drinks
- **Instant potato flakes:** Add to cream soups for more calories
- **Sweeteners (to change the taste and add calories):** Add extra sugar to tea, juices, and JELL-O. Use condensed sweetened milk in hot drinks. Use Karo syrup or honey in food or drinks. Use crushed up candy bars in milkshakes
- **Strawberry smash:** Mix together one-third cup strawberry drink mix and one-quarter cup applesauce



### *Thickened Liquids*

Thickened liquids move down the throat slowly and help prevent choking. Instant puddings, instant potato flakes, applesauce, JELL-O or gelatin can be added to foods/fluids. Patients can drink boiled custard, and JELL-O can be warmed to room temperature, stirred gently and served as a thickened liquid.

#### *Thickened-liquid suggestions:*

- Fruit purees or baby-food fruits
- Applesauce (to thicken fruit juices)
- Blended fruits (added to shakes or instant breakfast)
- Juices frozen in ice cube trays (to use in iced tea, lemonade, etc.)
- ***Banana shake:*** Mix together or use blender (if using blender, add two cups of ice cubes): two ripe bananas, sliced; 14 oz. condensed milk; one cup cold water; one-third cup lemon juice concentrate; one-half cup fortified milk; two scoops vanilla ice cream; and strawberry soda. Blend one-third cup strawberry-flavored drink mix with vanilla ice cream. Add carbonated water, if desired
- ***Orange/pineapple shake:*** Blend with crushed ice: one pint orange sherbet and three cups orange/pineapple juice
- ***Banana malt:*** Blend until smooth: one frozen banana; three-quarters cup fortified milk; and three tablespoons chocolate malted-milk power
- ***Chocolate/peanut-butter soda:*** Blend together: one-third cup Quik chocolate-flavored drink mix; one tablespoon peanut butter; one-quarter cup fortified milk; and two scoops vanilla ice cream
- ***Strawberry flip:*** Stir briskly: one-quarter cup strawberry drink mix; one tablespoon lemon juice; and one-third cup cold water. Add two scoops lemon sherbet. Add carbonated water, if desired. Top with whipped cream

- ***Quick breakfast drink:*** Blend together: one ripe banana, sliced; one tablespoon wheat germ; two teaspoons honey; and one-quarter teaspoon cinnamon
- ***Pudding shake:*** Mix with milk, as package directs: one box instant pudding, any flavor. Add one and one-half cups ice cream. Blend
- ***Spicy chocolate frosty:*** Blend together: one-quarter cup Quik chocolate-flavored drink mix; one cup fortified milk; and one-quarter teaspoon cinnamon. Add one scoop vanilla ice cream

*Other ways to add calories:*

- Add extra to toast: peanut butter, jelly, sugar and cinnamon
- Add cheese to sandwiches or put it in scrambled eggs. Put two to three slices of cheese in grilled-cheese sandwiches, instead of just one slice
- Use butter or gravy on potatoes or rice
- Use whole milk

***Do not use low-fat, low-sugar, or low-calorie foods***

***Fluids***

Hydration is important for a healthy body. It increases circulation, provides muscle tone and decreases constipation. Hydration is supplied by drinking beverages, soups, milkshakes or other liquids.

As the body changes with illness, the desire for food and fluid decreases. To artificially introduce fluids at this time can overtax the heart, lungs and kidneys. IV fluids are not always helpful.

*Rather than focusing on the consumption of liquids, offer the following for comfort:*

- Keep the mouth moist by moistening a washcloth for the patient to suck on
- If the patient is able to swallow, offer small amounts of fluids as frequently as tolerated. Use a syringe to give fluids or use ice chips
- Swab the mouth with toothettes soaked in water
- Keep the lips soft and moist with lip gel or balm, unless oxygen is in use. If oxygen is in use, patients must avoid using any product containing petroleum on lips or mouth
- Discuss concerns about hydration with your nurse

### *Swallowing Difficulties*

Difficulty swallowing can be the result of weakness and sometimes occurs as a side effect of certain medications or treatments. Patients may experience coughing, choking or pain during eating or drinking, making taking medications difficult.

***Notify your nurse immediately of any problems with swallowing.***

### *Helpful hints:*

- The patient should sit fully upright in bed or a chair before taking foods or liquids, and should remain upright for one hour after eating
- Before the patient eats or takes medication, try small sips of water. If coughing or choking occurs don't panic or slap the patient on the back. Try turning the patient on his or her side or bringing him or her into a more upright sitting position
- If the patient experiences choking problems, try tilting the patient's chin down while he or she swallows using a straw
- Thicker liquids are sometimes easier to swallow
- Milkshakes or gelatin liquids may help

- The blender can be used to puree foods. Other soft foods, such as puddings, mashed potatoes, applesauce or JELL-O are good
- Some medications (but not all) can be crushed and given in soft foods to make swallowing easier. Please be sure to check with your nurse before crushing any medications
- Sometimes medications are also available in liquid or suppository form, if swallowing is difficult



## PAIN CONTROL & MANAGEMENT

Pain can usually be controlled while allowing patients to remain awake and involved in the world around them. There are many myths about pain medication.

Here are some facts:

- Taking medication for pain will not make you a drug addict. Patients may need larger doses as time goes on and the body gets used to the medication. Increasing the amount of the medication to relieve pain does not indicate an addiction
- There will always be medication that can control the pain. There's no need to worry about a limit on the amount or type of medication being received. Many people take large doses of pain medication so they can remain comfortable and able to get up, walk around and do normal activities
- It is safe to take medication for pain — while following doctor's orders. Very large doses of medication can cause serious side effects, but if you follow your doctor's orders, you should have your pain controlled safely. Please contact your nurse or physician if you have questions about pain medication



- Pain medication should be given at regular times around the clock. The best way to control pain is to stop it before it starts. If the patient waits until the pain is severe, the medication has little chance to work. The goal is to prevent pain

Your nurse will ask the patient about the origin, location and duration of pain. The patient will also be asked to describe how severe pain is on a scale of zero to 10, with zero being pain free and 10 being very severe. Medication needed to control pain is different for each person and decided upon by the doctor. Prescriptions depend on:

- Diagnosis
- Age, height and weight
- How much pain the patient is experiencing
- Other medications being taken

Patients can help get relief from pain as soon as possible by remembering or writing down information about what seemed to make pain better or worse and how pain responded to various treatment efforts.

### *Pain Control*

Pain is a very personal experience and is different for everyone. Patients can expect their reports of pain to be believed by your Quality of Life Team.

The cause of pain varies. It can result from the disease or from treatment methods. Whatever the cause, most pain can be relieved or controlled. For this reason, patients are urged to discuss pain openly and honestly with the physician and nurse. We recommend keeping a pain journal.

### *Pain Journal*

Patients use the pain journal to track pain and the medications taken to control it. This record can help caregivers identify what methods are most effective, enabling them to respond quickly and accurately to pain and medication needs.

The patient or the family caregiver is asked to record information in the pain journal whenever pain is experienced. They should include information about what medication was taken for the pain. That entry should be followed about one to two hours later and record how well the medication worked. An entry should be made each time the patient has pain or takes medication.

### *Massage*

Massage can reduce stress and anxiety, distract a patient from thinking about pain, relax muscles and body, increase energy, improve alertness and increase blood flow. Ask your nurse about the availability of massage therapy or follow the directions below to provide a massage.

#### *How to massage:*

- Ask the patient where he or she would like the massage. Some people like a back massage, while others like their feet or hands massaged
- Put a warm lotion on the patient's body or your own hands; wear gloves
- Move your hands softly across the body
- Move your hands in gentle circles to improve blood flow
- Use a kneading motion, like the motion used to make bread dough
- Keep the patient warm and comfortable. Keep the rest of the body covered and warm while massaging each part of the body

## DISASTERS

Emergencies or disasters are unlikely, but always a possibility. In the event of an emergency or disaster, please contact your nurse and make him or her aware of your situation. Our staff can help you assess your needs and develop a plan.

### *Tornado Safety*

- Listen to your radio or TV for the latest weather updates
- Tornado Watch means local weather conditions exist for a tornado to develop. Tornado Warning means a tornado has actually been sighted or identified on radar
- In the event of a tornado, move away from all windows. Move toward an inner wall and cover up with pillows or a mattress, if able
- If possible, move to a room without windows or to the basement
- If a crisis occurs, call 911

### *Electrical Outage*

- Call the electric company to report outage problems
- If using an oxygen concentrator, switch to the backup oxygen tanks
- Call Hospice of Dayton or Hospice of Butler & Warren Counties so that we can alert the oxygen company to provide additional oxygen as needed
- If an alternative power supply is available, use it
- Keep a flashlight with working batteries ready for use
- Move to other housing, if necessary. We can help you set up emergency respite care
- If a crisis occurs, call 911

### *Gas*

- If you have lost service, or suspect a leak or damage to the gas lines or valves, call the gas company to report the problem
- If able, turn off the gas main valve
- Open windows
- Do not smoke or use an open flame (including candles, fireplaces and cooktops/ovens)
- Be prepared to leave home in the event of a leak
- Do not return to the home until the gas company has given you approval
- Inform the police and fire departments
- If a crisis occurs, call 911

### *Bathrooms*

- Install grab bars in showers, tubs and toilet areas to help with transferring the patient
- Always check the water temperature before entering a tub or shower. The U.S. Consumer Product Safety Commission recommends setting your water heater at 120 degrees Fahrenheit to prevent burns
- Consider a night light in the bathroom
- Consider using a shower chair/tub/bench
- Do not use bath oils. They are very slippery

### *Stairs and Hallways*

- Keep stairs and halls clear and well lit
- Make sure stairs have well-secured rails on both sides
- Avoid using the stairs wearing only socks, loose slippers or smooth-soled shoes

### *Outdoors*

- Entryways should be well lit and clear of debris, ice, leaves and snow
- Provide secure outside step and porch railings
- Make sure the street address is clearly marked and visible from the street both day and night

# D. ADDITIONAL INFORMATION





## Patient Bill of Rights & Responsibilities

Hospice organizations have an obligation to protect and promote the rights of patients. Patients have a right to:

- Be treated with dignity and respect at all times
- Receive care of the highest quality from appropriately trained and certified medical professionals
- Receive care in a safe environment free from all forms of abuse, neglect, exploitation or mistreatment
- Be notified in writing of the care to be provided, with information about the professional caregivers who will furnish care and the frequency that such services will be provided
- Participate in the planning of their care
- Be informed of the benefits and risks of all treatment options of their care
- Expect their choices as specified in an advance directive will be honored
- Refuse services and be advised of the consequences of refusing care
- Be told what to do in case of an emergency
- Expect relationships with Hospice caregivers to be based on honesty and ethical standards of conduct
- Confidentiality regarding information about their health, social, financial circumstances and about what takes place in their home
- Protection of their privacy consistent with requirements of state and national laws
- Request changes in professional caregivers without fear of reprisal or discrimination
- Voice grievances without fear of discrimination or reprisal for having done so

- Be informed of procedures to follow in lodging a complaint with the Hospice provider about care
- Be informed of any charges not covered by Medicare, Medicaid or any other payer for which they may be responsible
- Receive information regarding any changes in policies affecting charges
- Receive on request all bills for services received regardless of whether bills are being paid out of pocket or by another party
- Be informed of the Hospice's ownership status and its affiliation with any entities to which the patient is referred

Hospice patients and families should be aware that:

- Please ask us if you do not understand information. We will be happy to answer your questions
- Active participation by the patient is important to the management of pain and symptoms and the effectiveness of treatment
- All information provided by the patient and family should be complete and accurate, including information pertaining to health and medical history, current condition, past illnesses, hospital stays, medicines, vitamins, herbal products and other matters pertaining to health, including perceived safety risks
- All information provided by the patient and family regarding health insurance coverage should be complete and accurate
- A copy of your advance directive should be provided to your physician and Hospice provider to assure your wishes are honored. The Hospice team can assist in developing an advance directive if one is not already in place
- Unless provided or arranged by the Hospice, some treatments, testing or medications may result in charges for which the patient or family will be responsible
- Hospice caregivers are prohibited from accepting personal gifts and borrowing or accepting money from patients/families/family caregivers



The patient and family and Hospice provider share the responsibilities of:

- Courtesy for each other in all interactions
- Honest and respectful communication
- Respect for the time of each other by notifying each other of changes in visit schedules or appointments
- Respect and consideration for property belonging to each other
- Assuring a safe environment during the course of patient treatment, care and services



## Discharge

### *Discharge Policy*

Medicare and other insurance providers work with our team to monitor patient progress. Sometimes a patient's condition stabilizes or improves, becoming chronic in nature. When this happens, we are required to discharge the patient from the Hospice program. Upon discharge, our staff works with the patient and family to assist in finding other support services to ensure the patient continues to receive quality care.



## Payments & Assistance

### FINANCIAL RESPONSIBILITY & PAYMENT INFORMATION

#### *Who pays for the cost of Hospice care?*

We provide our services to any patient who is eligible for Hospice care and who meets Hospice admission criteria, regardless of the patient's ability to pay. Our services are reimbursed by Medicare, Medicaid and most private insurances.

The Medicare/Medicaid hospice benefit covers the following services at 100%:

- All medications related to your terminal diagnosis
- Nursing, social worker and home health aide visits
- Counseling and emotional support
- All medical supplies, equipment and appliances related to a terminal diagnosis
- All visits by our physicians
- Dietary counseling
- Physical, occupational and speech therapies
- Crisis Care when necessary and ordered by your physician during crisis periods
- Non-emergency ambulance transport for medical treatment related to your terminal diagnosis
- Short-term in-patient care for symptom management at the Hospice House in Dayton, Lorelei's Place Hospice House in Franklin, serving Hospice of Butler & Warren Counties, or other contracted in-patient facilities in our communities
- Laboratory tests, x-rays and procedures needed to manage symptoms
- Services of consultant physicians
- Respite care

## Ethics & Privacy

### CODE OF ETHICS

Your Quality of Life Team is fully committed to the Hospice and Palliative Care Organization Code of Ethics.

#### *I. To meet the hospice and palliative-care needs of patients and their families:*

- To remain sensitive to and be appreciative of the ethnic, cultural, religious, spiritual and lifestyle diversity of patients and their families
- To honor the wishes, concerns, priorities and values of patients and their families
- To support, affirm and empower families as caregivers
- To acknowledge and respond with sensitivity to the interruption of privacy that is necessitated by care at home; to enter no further into family life and affairs than is required to meet the goals of the plan of care
- To respect and protect the confidentiality of information concerning patients and families
- To provide quality hospice and palliative-care services in a timely manner to all who qualify, regardless of race, religion, sexual orientation, ethnic background or ability to pay

#### *II. To act honestly, truthfully and fairly to all concerned:*

- To fully disclose to patients and families information regarding cost, services and complaint policies, as well as policies regarding discontinuation of service
- To honestly and conscientiously cooperate in providing information about referrals and to work with other agencies to ensure comprehensive services to patients and families

- To be truthful and accurate in public advertising and information dissemination
- To make and accept referrals solely in the best interest of patients
- To refrain from giving or accepting gifts of value or monetary compensation for the purpose of obtaining or making referrals
- To ensure that hospice services are not diluted for financial reasons

*III. To instruct both local and national communities in the tenets of hospice and palliative-care philosophy:*

- To encourage dialogue about hospice and palliative care in all appropriate public forums
- To encourage inclusion of hospice and palliative care in all federal, state and commercial healthcare plans
- To provide consumers with sufficient information about hospice and palliative care to enable true informed consent
- To act as a liaison in consumer discussions concerning end-of-life care decisions
- To assume a leadership role in ensuring access to hospice and palliative care for all people facing the end of life
- To serve on committees or in groups concerned with policy-making decisions, which will affect healthcare in this country

*IV. To continuously strive for the highest level of skill and expertise of the staff and volunteers in the delivery of care:*

- To recruit, select, orient, educate and evaluate each staff member and volunteer to ensure competency, based on identified job requirements
- To remain sensitive to and be appreciative of the ethnic, cultural, religious, spiritual and lifestyle diversity of staff and volunteers

- To support, affirm and empower staff and volunteers in the delivery of care
- To recognize the unique stressors inherent in hospice and palliative-care work and provide access to ongoing support for all staff and volunteers
- To ensure that contracted providers are properly trained and qualified and that they provide care consistent with the values and philosophy of hospice and palliative care

## PRIVACY PRACTICES

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

Hospice of Dayton and Hospice of Butler & Warren Counties use Protected Health Information (PHI) about you for treatment, to obtain payment for treatment, for administrative purposes, and to evaluate the quality of care that you receive.

Your PHI is contained in medical and billing records that are the physical property of your hospice provider and that may identify you or may describe or be related to your past, present or future physical and mental health.

***Hospice of Dayton and Hospice of Butler & Warren Counties are required by law to:***

- Maintain the privacy of your PHI
- Provide you with this notice of its legal duties and privacy practices with respect to your PHI
- Abide by the terms as described
- Notify you if we are unable to agree to a requested restriction on how your PHI is used or disclosed
- Accommodate reasonable requests you may make to communicate PHI by alternative means or at alternative locations
- Obtain your written authorization to use or disclose your PHI for reasons other than those listed herein and permitted under law
- We reserve the right to change information practices and to make the new provisions effective for all protected health information it maintains

- ***Revised notices will be made available by*** a member of the Quality of Life team (to current patients)
- Posting on the Hospice of Dayton and Hospice of Butler & Warren Counties' websites
- Posting within our facilities

## HOW WE MAY USE OR DISCLOSE YOUR HEALTH INFORMATION

### *For Treatment*

Hospice of Dayton and Hospice of Butler & Warren Counties may use your PHI to provide you with medical treatment or services or provide your PHI to other healthcare providers who are involved in taking care of you. For example, a healthcare provider, such as a physician, nurse or other person providing health services to you, will record PHI in your record that is related to your treatment. This information is necessary for these healthcare providers to determine what treatment you should receive. This PHI may also be provided to other healthcare providers, so that they can treat you. You will be asked to sign consent to provide treatment and to permit this.





### *For payment*

Your health information may be used and disclosed to others for purposes of receiving payment for treatment and services that you receive. For example, a bill may be sent to you or a third-party payer, such as an insurance company or health plan. The information on the bill may contain information that identifies you, your diagnosis and treatment or supplies used in the course of treatment.

### *For Healthcare Operations*

Your PHI may be used or disclosed for the business of hospice operations. For example, your PHI may be disclosed to members of the medical staff, risk or quality-improvement personnel, and others to:

- Evaluate the performance of our staff
- Assess the quality of care and outcomes in your case and similar cases
- Learn how to improve our facilities and services
- Determine how to continually improve the quality and effectiveness of the healthcare we provide
- Type out notes and documents to help Hospice of Dayton and/or Hospice of Butler & Warren Counties keep accurate records

### *Appointments*

Your PHI may be used to provide appointment reminders or information about treatment alternatives or other health-related benefits and services that may be of interest to you.

### *Fundraising*

Your PHI may be used to contact you, your caregiver and/or friends listed in your PHI database to generate funds to support needed programs and services benefitting patients and families cared for by Hospice of Dayton or Hospice of Butler & Warren Counties.



### *Group Health Plans*

A group health plan, health-insurance issuer or HMO with respect to a group health plan may disclose PHI to the sponsor of the plan.

### *Required by Law*

We may use and disclose PHI about you as required by law for the following, including:

- For judicial and administrative proceedings pursuant to legal authority
- To report information related to victims of abuse, neglect or domestic violence
- To assist law-enforcement officials in their law-enforcement duties

### *Public Health*

Your PHI may be used or disclosed for public-health activities, such as assisting public-health authorities or other legal authorities to prevent or control disease, injury or disability, or for other health oversight activities.

### *Decedents*

PHI may be disclosed to funeral directors or coroners to enable them to carry out their lawful duties.

### *Organ/tissue Donation*

Your PHI may be used or disclosed for cadaver organ, eye or tissue donation purposes.

### *Research*

Your PHI may be used or disclosed for research purposes with your authorization when an institutional review board or privacy board that has reviewed the research proposal and established protocols to ensure the privacy of your health information has approved the research.

### *Health and Safety*

Your PHI may be disclosed to avert a serious threat to the health or safety of you or any other person, pursuant to applicable law.

### *Government Functions*

Your PHI may be disclosed for specialized government functions, such as protection of public officials or reporting to various branches of the armed services.

### *Workers' Compensation*

Your PHI may be used or disclosed in order to comply with laws and regulations related to Workers' Compensation.

### *Other Uses*

Other uses and disclosures will be made only with your written authorization, and you may revoke the authorization except to the extent Hospice of Dayton or Hospice of Butler & Warren Counties has taken in prior action reliance on such.

## **YOUR HEALTH INFORMATION RIGHTS**

You have the right to:

- Request a restriction on certain uses and disclosures of your PHI, which must be submitted in writing, on forms to be provided by your hospice provider; however, your hospice provider is not required to agree to a requested restriction
- Request a limit on the PHI that may be disclosed about you for treatment, payment or healthcare operations to someone who is involved in your care or payment for your care
- Obtain a paper copy of the notice of privacy practices for any reason, upon request to your hospice provider
- Inspect and obtain a copy of your health record, containing PHI, using the request form we furnish to you. We will notify you in writing, within 60 days of our decision, including our rejection of your request. You may appeal this request. You may also be charged for any copies of PHI provided to you
- Amend your health record, using a form prepared by your hospice provider

- Request communications of your health information by alternative means or at alternative locations, which will be accommodated on a reasonable basis
- Revoke your authorization to use or disclose health information, except to the extent that action has already been taken, and receive an account of disclosures made of your health information as provided by 45 CFR §164.528

## LIVING WILL, DURABLE POWER OF ATTORNEY & ALLOW NATURAL DEATH POLICIES

We respect each patient's wishes to decline life-prolonging interventions to the extent allowed by law and the organization's mission and philosophy.

Such wishes should be clearly defined in a valid advanced directive document (living will and/or durable power of attorney or Allow Natural Death document).

Your Quality of Life Team will assist you in considering or developing an advance directive and/or Allow Natural Death (AND) document, if you desire.

***You do not need a living will, durable power of attorney or AND document to be admitted to our program.***

## COMPLAINT PROCEDURES

We are focused on our patients' and their caregivers' well-being. It's our primary focus to provide optimum care that's designed to meet your needs. However, if you need to issue a complaint, you may contact Hospice of Dayton, Hospice of Butler & Warren Counties and the Department of Health and Human Services if you believe your privacy rights have been violated. You will not be retaliated against for filing a complaint.

***If you have any questions or complaints, please contact:***

Privacy Officer  
Hospice of Dayton  
324 Wilmington Avenue  
Dayton, Ohio 45420

937-256-4490

Privacy Officer  
Hospice of Butler & Warren Counties  
5940 Long Meadow Drive  
Franklin, Ohio 45005

513-422-0300

## Donations to Our Programs

### *Support of Our Mission*

Our ability to provide one-of-a-kind healing programs to patients and families relies on support from the community. The Hospice of Dayton Foundation is the charitable arm that provides the philanthropic foundation for both Hospice of Dayton and Hospice of Butler & Warren Counties. There are so many ways you can help support our mission and assure that our care is available for generations to come to anyone in need, regardless of ability to pay.

### *Memorial Gifts*

One of the most meaningful ways to support our mission and remember a loved one is to request memorial contributions be made in honor of an event such as a birthday, anniversary or special holiday by giving an annual gift.

### *Gifts in Honor*

Giving a gift “in honor of” someone special is an expression of love and affection for a family member or friend that carries meaning and weight to recognize a milestone or an achievement.

### *Memorial Gardens, Plaques and Naming Opportunities*

As you tour the grounds of our Hospice Houses, you will notice opportunities to honor a special person in your life. All proceeds from these donations are used to support the special programs that Hospice of Dayton and Hospice of Butler & Warren Counties offer to the community. If you would like information about memorial gardens, plaques or other naming opportunities, please call the Hospice of Dayton Foundation at 937-258-5537.

### *Matching Gifts*

Many employers offer a matching-gift program. You can double the value of your donation by asking for an appropriate form, completing it and enclosing it with your check.

### *Heirlooms Shoppes*

Our Heirlooms Shoppes accept donations and sell gently used furnishings, home accessories, antiques, collectibles, vintage clothing, jewelry and artwork. Donations can be tax deductible and all proceeds from sales go directly toward patient services. Similarly, proceeds from our Hospice House Heartfelt Gifts Heirlooms Shoppe are also earmarked to support patient care.



### *Sponsorships/Gifts in Kind*

Gifts of goods and services for our special events can qualify you or your organization for a sponsorship listing and/or tax deduction.

### *Planned Giving or Deferred Gifts*

There are many ways to leave a legacy through planned giving. Contributions can be arranged during your lifetime, but may not be received in entirety during that time. Many donors discover financial advantages through planned giving.

### *Gift Annuities*

A charitable gift annuity enables you to make a donation while receiving a fixed dollar amount annually from the Hospice of Dayton Foundation. A simple contract can be drafted between an individual and the Foundation to establish a gift annuity.

### *Wills/Bequests*

When creating your estate, you can consider specifying an amount or percentage of your estate as a gift to the Hospice of Dayton Foundation.

### *Life Insurance*

By naming Hospice of Dayton or Hospice of Butler & Warren Counties as a beneficiary on a life-insurance policy, you can create a lasting legacy gift. Proceeds will only transfer to the organization upon your death, enabling you to impact your community beyond your natural life.

### *Events*

Throughout the year, Hospice of Dayton and Hospice of Butler & Warren Counties host events and family friendly activities that enable supporters to donate while enjoying a special event. You may receive invitations or information relating to such events or other information about charitable support opportunities. The members of our Hospice of Dayton Foundation staff

are available at 937-258-5537 for additional information. Foundation President Brenda Humfleet will be happy to establish a time to meet to discuss inquiries and donor options that might be meaningful to you.

You have the option to refuse to receive fundraising materials and communications and can request we remove your name from our mailings by contacting the Hospice of Dayton Foundation at 937-258-5537.

### *Remembrance and Naming Opportunities*

We are pleased to share a variety of options for honoring the memory of your loved one. We are currently creating new landscapes surrounding our Hospice House in Dayton and Lorelei's Place in Franklin, Ohio. These unique and breathtaking landscapes will be enjoyed by family, friends and patients. There are a variety of naming opportunities to memorialize and/or honor your family or loved one. Naming features include: waterfalls; indoor and outdoor water features/fountains; butterfly gardens; Japanese gardens; rose gardens; patient solarium; outdoor chapel gardens; and vertical displays.

### *Donations of Medical Supplies and Equipment*

There are several local charities that would welcome your donation of the following: adult diapers and under pads, dressings, nutritional formula, tube feeding supplies, oxygen tubing and trach supplies, suction catheters, urinary catheters, ostomy supplies, wheelchairs, walkers, canes, clothing and toiletries. Please contact us at 937-258-4989 or 877-445-5086 for additional information about donating such supplies and equipment.

If you would like to speak personally with a member of our Foundation staff about options to honor and memorialize your family or loved one, please contact us at 937-258-5537 or email us at [bhumfleet@hospiceofdayton.org](mailto:bhumfleet@hospiceofdayton.org).

*Thank you for choosing to help us bring expert care, peace of mind, comfort, and hope to others who are affected by life threatening and life limiting illness.*





# E. INDEX







877-445-5086  
[www.hospiceofdayton.org](http://www.hospiceofdayton.org)