

# PATIENT & CAREGIVER GUIDE

A training guide for care at the end of life



ARBOR  
HOSPICE

# Welcome to Arbor Hospice

## HOW TO CALL:

Arbor Hospice Contact Center: **888-992-CARE (2273)**

Your Team: \_\_\_\_\_

No matter where you live, call this number. This number is answered 24 hours a day, seven days a week. When you call, you will have an opportunity to speak with a triage nurse who will answer your questions and address your concerns.

## WHEN YOU CALL:

When you call the Arbor Hospice Contact Center, please provide your name, the patient's name, and the reason for your call.

## YOUR CARE TEAM:

Registered Nurse Case Manager: \_\_\_\_\_

Social worker: \_\_\_\_\_

Hospice aide: \_\_\_\_\_

Volunteer: \_\_\_\_\_

Spiritual care advisor: \_\_\_\_\_

Others: \_\_\_\_\_  
\_\_\_\_\_

Operations Manager: \_\_\_\_\_

## CARE FROM ARBOR HOSPICE IS:

- Accessible at any time — 24 hours a day, 7 days a week
- Preventing and managing pain and symptoms to improve quality of life
- Committed to your physical, emotional and spiritual comfort
- Focused on helping you live your way

**Disclaimer.** The purpose of this publication is to offer general information and recommendations concerning the subject matters covered. This publication is provided with the understanding that **Arbor Hospice** is not providing medical or other professional advice to meet the needs of specific patients or caregivers. If medical or professional advice is needed, please call your physician or the 24/7 Contact Center telephone number noted above.

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## Part 1: Introduction to Arbor Hospice

Thank you for asking Arbor Hospice to help. We will work with you as partners in your care.

When you are seriously ill, it is natural to have fears about the future. When your loved one is ill, you may doubt that you will be able to keep him or her comfortable and, at the same time, keep up with everyday tasks. Hospice will provide information to ease your fears. We will provide help to keep family and caregivers from feeling overwhelmed.

Together, we will plan. We will be with you. We will help.

### THE ARBOR HOSPICE TEAM

Arbor Hospice services are provided by care teams. Because illness affects much more than physical health, care teams are made up of people with different kinds of training and skills. Members of your care team will visit regularly. Together, you will decide who visits and how often. All of the members of your care team share the responsibility for providing care of the highest quality.

Your own physician may be a part of this team. You and your physician can decide whether he or she will continue to be in charge of your day-to-day care when you select Arbor Hospice to help manage your care.

If you desire, the Arbor Hospice **physician** can be in charge of your care once you select hospice care. Whatever your choice, the Hospice physician will be aware of your care through routine team conferences.

Your Arbor Hospice **registered nurse case manager** (RNCM) will focus on providing skilled care and support related to your physical condition, level of comfort, and learning needs. Your RNCM will perform physical assessments, ask for your input on planned treatments and medication changes, communicate with your physician, and help you

find answers to your questions. Your RNCM is an excellent source of information about medications, treatments, disease processes, equipment use, hands-on care, and other topics of concern.

**Social workers** help families cope with emotional, legal and financial issues. When sudden legal and financial problems arise, social workers will – with your consent – coordinate with church programs, community agencies and resources for help. A hospice social worker can review your health insurance coverage and – if you have the means – help arrange privately-paid services Arbor Hospice cannot provide.

Social workers are also trained to help families cope with stress. They work with adults and children to minimize conflicts and keep the family working together. Anxiety and stress often lead to frustrations. Don't hesitate to ask for help. Almost all the families we work with spend some time with a Arbor Hospice social worker.

**Spiritual care advisors** support patients and families by helping to identify the things that are important and meaningful to them and drawing on these factors for strength in times of distress. One does not need to be part of an organized religion or faith to work with a spiritual care advisor. If organized religion is an important part of your life, the Arbor Hospice spiritual care advisor will work with your pastor, priest, rabbi or other religious leader.

**Hospice aides** make your personal care and comfort their highest priority. They assist with personal care (such as bathing, dressing, shaving and hair care), change bed linens and help with repositioning the patient. They assist with meal set-up and feeding as needed. Visits with your hospice aide may be a good time for a walk, wheelchair ride outside or other activity that may be difficult without assistance. Hospice aides are valuable sources of practical information and encouragement.

**Arbor Hospice volunteers** are men and women of all ages with all kinds of skills and talents. Arbor Hospice volunteers are specially trained to provide assistance and support. From companionship to running errands, their roles are guided by your needs. You can ask for a volunteer by talking with a member of your care team.

### **After-hours / On-call**

Support from Arbor Hospice is available 24/7. Our after-hours on-call and weekend care teams ensure that you have access to skilled, knowledgeable Arbor Hospice staff whenever needed.

### **Integrative Therapies**

In addition to traditional treatment options such as medical intervention, Arbor Hospice offers a variety of alternative pain management therapies, including music therapy, massage therapy and pet visits. These integrative therapies are utilized alongside our medical interventions to provide patients with a holistic plan of care. Integrative therapies help patients control symptoms of their disease, deal with stress and relieve anxiety. Integrative therapies may be part of your plan of care based on need and availability.

**Grief Journey Program staff and volunteers** assist those who express a desire for support in coping with their grief and loss experiences. Home visits, phone calls, grief support groups and mailings are among the many services offered by Arbor Hospice's Grief Journey Program staff.

## **HOW OFTEN WILL ARBOR HOSPICE STAFF COME TO OUR HOUSE?**

After you are admitted into hospice care, your RNCM will work with you to develop a plan of care, which includes how often visits by the care team will be scheduled. The RNCM will discuss this plan with your physician.

Keep in mind that your family still provides most of the daily care and that Arbor Hospice staff will not be with you 24 hours a day. Your care team will provide you with the education, tools and support needed to focus on making the most of each day. Your care team will work with you to continually assess the plan of care and make adjustments as necessary. Some families may choose to hire aides or nurses for around-the-clock care. When this is the case, they too are supported by the hospice professionals.

## **WHAT IF THERE IS NO HOUSE?**

Arbor Hospice provides care in many settings. It may be the patient's home or a family residence. It may also be an assisted living facility, a nursing home or a hospital. Care provided by the Hospice team is usually paid for by insurance. Providing a place for the patient to live is usually a family's responsibility. Medicaid may pay for a nursing home for families that qualify.

Hospice staff provide the same attentive care no matter where your loved one lives.

## **INSURANCE AND REIMBURSEMENT ISSUES**

Both Medicare and Medicaid have a hospice benefit. Medicare and Medicaid together pay for more than 90 percent of all hospice care provided in Michigan. Hospice care is also reimbursed by many other types of health plans, including health maintenance organizations (HMOs), preferred provider organizations (PPOs), Blue Cross and Blue Shield of Michigan and other private insurance companies. If you have insurance other than Medicare (Part A) or Medicaid, we will help you determine your coverage by contacting your insurance company for you.

Generally, hospice care insurance pays for everything related to the management of symptoms of the terminal illness. Since our philosophy is to provide access to all who choose this type of care, regardless of ability to pay, we also work toward providing care for those who have no hospice benefit coverage.



Staff will work to determine financial resources and patient care needs and to inform you of any anticipated expenses. Grief support services are free of charge.

Eligibility for hospice care is described in regulations that were developed for the Medicare Hospice Benefit, and many of those rules apply to Medicaid and various private insurance plans. Most health plans are similar to those provided under Medicare, but coverage varies. To ease your concerns, admissions staff, patient finance staff and social workers will work with you and your family to try to ensure that payment issues are handled in a quick and uncomplicated manner. We believe that payment for services should not be a major concern for you at this time of life.

## LEVELS OF CARE

As a licensed and certified hospice, Arbor Hospice provides extensive services in various locations to meet the routine needs of our patients and their families. Most patients receive care where they live, either at home, in an assisted living facility or a skilled nursing facility.

As a licensed and certified provider, Arbor Hospice provides four levels of care:

- **Routine Care:** This is care provided by a caregiver at the patient's place of residence with assistance from the hospice team.
- **Continuous Care:** This is skilled nursing service provided at the patient's residence for a short duration to help manage symptoms. Arbor Hospice does not have the ability to provide continuous home care services for other than short-term intervention. Patients needing continuous home care for long-term care will be referred to other community agencies to help meet the patient's needs.

- **General Inpatient Care:** This is care provided for pain control or other acute symptom management that cannot feasibly be provided in any other setting. Inpatient care begins when other efforts to manage symptoms have been ineffective.
- **Respite Care:** Respite care is short-term care provided in an approved facility only when necessary to relieve the family members or other persons who normally care for the individual at home. Respite care may be provided for up to five consecutive days at a time.

## **CPR AND DO-NOT-RESUSCITATE (DNR) DECISIONS**

CPR – cardiopulmonary resuscitation – refers to the medical procedures used to attempt to restart a patient’s heart and breathing when the patient suffers heart failure. CPR may involve simple efforts such as mouth-to-mouth resuscitation and external chest compression.

A Do-Not-Resuscitate (DNR) order tells medical professionals NOT to perform CPR. This means that doctors, nurses and emergency medical personnel will not attempt emergency CPR if the patient’s breathing or heartbeat stops.

DNR orders may be written for patients in a hospital or nursing home, or for patients at home. Hospital DNR orders tell the medical staff not to perform CPR if cardiac arrest occurs. If the patient is in a nursing home or at home, a DNR order tells the staff and emergency medical personnel not to perform emergency resuscitation and not to transfer the patient to a hospital for CPR. Hospice staff do not perform CPR as part of the hospice plan of care, but can assist in calling 911, if that is your desire. Upon enrollment in hospice, patients will be given the option to sign a DNR order.

## HOW TO USE THIS BOOK

As you will see, parts of this book are addressed to the person who is ill and parts are directed to the caregivers. Some parts are for both. Unlike in a hospital, where the patient is always a patient and a nurse is always the caregiver, in hospice home care, the roles are less sharply defined. Sometimes the family or caregivers need care as well as the patient. And occasionally, patients provide their own care. We want to remember that the person who is ill is a member of a family, of friends and relatives.

Your nurse will help you decide which sections to read first. Most of our families read the entire book. We hope you will use the information as your family needs it. It is a valuable resource in partnering with you for your loved one's care.

## CAREGIVERS NEED HELP TOO!

For your own well-being and that of your loved one, you need to think about your needs and feelings and discuss them with a care team member. If last week you told the hospice team that you had no need for help, but today you are feeling swamped and fearful, call the hospice office. Someone will make a plan with you to try and help.

Here are some steps caregivers can take for their own well-being:

- Ask other family members and friends to help you with routine chores. For example, they can assist with the laundry or the grocery shopping or fix a meal for you. Many people are eager to help you, but they may wait to be asked. If it's hard for you to ask for relief, let the hospice staff help with arrangements.
- What if you ask and they don't come? Some friends and relatives may be so uncomfortable with the illness that they won't want to visit. A hospice staff member may be able to help you understand their feelings so that you avoid becoming angry with them.

- A caregiver's sleep is very important. If your loved one sleeps a lot during the day, try to take a nap at the same time. If caring for your loved one makes sleeping difficult, ask Arbor Hospice for help. A neighbor or friend or a hospice aide or volunteer may be able to give you some time off. You may decide to hire some additional help.
- Try to take at least a few hours a week to get away from the house. The time away may give you renewed energy and motivation to care for your loved one. Again, ask for help from family, friends or Arbor Hospice to give you a chance to renew your spirit.

With Arbor Hospice you are never alone. You can call us any time and a nurse or other staff member will be available to help you. If necessary, a hospice staff member can visit, even in the middle of the night.

## **INVOLVE THE CHILDREN**

Children in the family may be frightened by the illness and upset by changes in the family's routine. These suggestions may help lessen their fears:

- Let them visit and provide care if they want to, even if it's something as simple as bringing a glass of water to the patient.
- Answer their questions honestly in a way they can understand.
- Try to give them extra comfort and affection.
- Be sure to tell teachers or day care providers about the situation.

If children are having trouble at school or in their relationships with friends, or if their eating and sleeping habits suddenly change, call Hospice. A member of our team or a counselor may be able to help, or be able to connect you with other community resources.

## Part 2: Working with Arbor Hospice

### **CALL HOSPICE FIRST! 888-992-CARE (2273)**

No matter what the time or day of the week, the Arbor Hospice phone will be answered.

Although you always have the option of calling 911, we suggest you call Arbor Hospice first, for any situation.

If there is a sudden change in the patient's condition, or for any of the reasons listed below, or just because you need someone – call Arbor Hospice. A professional member of the team is there to help answer your questions. He or she might arrange for a visit (Arbor Hospice staff visit at all hours of the day and night) or connect you with the appropriate staff member.

### **WHEN I CALL, WILL THEY KNOW WHO I AM?**

One of the most frequent complaints about health care is that no one in the clinic or hospital knows the patient; they have to repeat their story over and over again. For that reason, whenever you call Arbor Hospice, we are able to access your electronic records which provide all the relevant patient information and history so we can best address your needs. During normal business hours (Monday-Friday, 8am-5pm), your RNCM will be closely following your care. After hours and on weekends, our “on call” staff members will have access to your medical records and are available to answer questions as well.

## **WHAT IF I AM NOT SURE ABOUT CALLING?**

There are no “dumb” questions! If it’s important to you, it’s important to the hospice staff. So please call and let us try and help.

### **WHEN TO CALL:**

What should you do about sudden symptoms, increased pain, family crises and feelings of depression? CALL ARBOR HOSPICE! Call anytime, day or night – even on Sunday or a holiday.

### **CALL ARBOR HOSPICE IF THE PERSON WHO IS ILL:**

- has increased pain in spite of taking prescribed medications
- suddenly is more short of breath or experiences anxiety and restlessness
- vomits more than once in an eight-hour period
- has more than one loose, watery stool within eight hours
- is eating, but has not had a bowel movement in three days
- complains of a sore mouth or has difficulty swallowing
- has broken skin or a red area
- doesn’t urinate or there is no urine in the collection bag for five hours
- has an unexpected loss of consciousness and/or seizures
- has bleeding that does not stop or a quantity of blood loss that disturbs you
- expresses suicidal thoughts, feelings of guilt or hopelessness
- has a continuous fever (greater than 100.5°)
- has troublesome symptoms that persist or medication side effects are noted (for example, diarrhea or rash)

## **CALL ARBOR HOSPICE IF:**

- the caregiver is feeling so bad or so stressed that he or she is having trouble managing
- children's eating or sleeping habits change or they are having trouble in school
- family members are depressed and not able to carry on with activities of daily living
- there is a family crisis

## **WHAT IF I HAVE AN UNRESOLVED PROBLEM OR A COMPLAINT?**

If you have a complaint, or something is not right, please tell us immediately. Begin by speaking directly with any member of your care team, or you may ask to speak with the team's Operations Manager.

Be as specific as you can about your complaint. Include the date, time and names of people involved. If you need help putting your complaint in writing, let us know.

If you are not satisfied with the response that was received from the Operations Manager, you may contact the Director of Organizational Integrity at 888-992-2273 during regular business hours, Monday through Friday.

For more information on filing a complaint, please refer to page 13 of the comprehensive guide provided at admission titled *EXCELLENT CARE BEGINS WITH HELPFUL ANSWERS: LEARN OUR APPROACH TO HOSPICE CARE*

PART  
2

If the Hospice staff has not resolved your complaint/grievance to your satisfaction, you can call the Michigan Department of Licensing and Regulatory Affairs at 800-882-6006 with a complaint. You do not need to cite a specific violation of a code or state law to file a complaint.

You also have the option of contacting our accrediting agency, Community Health Accreditation Partner, at (800) 656-9656 or visit [www.chapinc.org](http://www.chapinc.org).

Your peace of mind is very important to us. Please tell us immediately if something is not right.



## Part 3: Daily Care

### CREATING A “PLACE” FOR THE PERSON WHO IS ILL

When you choose hospice care, you may have some new and special needs. Previous living and sleeping arrangements may need to be modified to make care easier and more comfortable for everyone.

The “place” for the person receiving Arbor Hospice care may be anywhere in the home: the living room in a recliner chair, the family room in a hospital bed or the bedroom with its familiar surroundings. The important point to remember is that it should be comfortable for the patient and accessible for the caregiver.

Consider some of the following questions when you prepare this place:

- Does the person wish for privacy?
- Does the person want to be with the family?
- Does the person have to walk far to meet various needs?
- Can caregivers easily provide care in the chosen location?
- Does the caregiver and patient have easy access to a bathroom?

Remember that this is a temporary location. Needs may change over time. Consider the comfort of the person who is ill and the rest of the family.

### SUPPLIES AND EQUIPMENT

Care is easier and better if you have the right equipment. Your physician or hospice nurse will help you decide what equipment you will need. Your hospice benefit covers most equipment you may need, but not everything.

Arbor Hospice has contracts with high-quality suppliers who respond quickly to your needs. All equipment covered by your hospice benefit will come from these companies.

If your needs change, tell us. We will be happy to arrange new equipment to meet your new needs. When you no longer need a piece of equipment, please let Hospice know and we will arrange for a pick-up. NOTE: Our medical equipment partners have up to 48 hours from the time of notification by Arbor Hospice to pick up any equipment.

Payment for items that are not covered will be discussed with you.

## **SAFETY IN THE HOME**

Providing care in the home for someone whose physical or mental faculties are declining creates new and special safety needs. A phone near your loved one's bed would enable him or her to summon assistance. Please read this section carefully.

### **Prevent fires and burns**

- Use smoke alarms and check batteries routinely.
- Don't smoke in bed or in a recliner.
- Have an escape plan and practice it.
- Post emergency numbers near your phone.
- Follow all instructions for safe use of space heaters.
- Don't use the kitchen stove for heating the house.
- Test water temperature before using.
- Use stove carefully.
- Store flammable items away from heat.
- No open flames should be used within 5 feet of oxygen equipment.
- Install fire extinguishers.

### Prevent electrical injuries

- Cover unused outlets.
- Do not use frayed or broken cords.
- Do not overload electrical outlets.
- Do not use electrical equipment near water.
- Follow all instructions for safe use of medical equipment.
- Call for help if fuses blow or lights dim frequently.

### Prevent slips and falls

- Keep walkways and stairs free of clutter and cords.
- Use handrails.
- Remove or secure throw rugs.
- Wipe up spills.
- Make sure rooms are well-lit.
- Change positions slowly and allow for appropriate rest periods
- Know how to use mobility equipment safely (walkers or canes).
- Use grips, tread, shower bench or elevated toilet seat if needed in bathroom.
- Wheels of beds, wheelchairs, etc. should be locked when stationary.
- Tubs and showers used for patient care should have textured surfaces and non-skid mats.
- Assist the person when standing or walking.
- Consider installing grab bars in the bath or near the toilet.
- Avoid slippery floors.
- Choose footwear with light-non-slip soles.
- Sleep near the person who is ill.

**Poison prevention/medication safety**

- Caregivers should know the name, dose, route, purpose, schedule and major side effects of all medications.
- Keep a list of medications which cause an adverse or allergic reaction
- Do not stop, increase or decrease your medications without your physician's consent.
- Have your medications refilled before they are completely gone.
- Do not take any medications that are prescribed for someone else, and do not offer your prescribed medication to anyone else.
- Store medicines in labeled container in a dry area and avoid extreme temperatures.
- Store medications, cleaning and other household chemicals away from children and pets.
- Store chemicals in labeled and proper containers.
- Notify your Arbor Hospice nurse if medications have expired.
- Call hospice immediately if the wrong medication or an incorrect dose is given.
- Your nurse can assist you with a written medication schedule/system if needed.

**NOTE: Please refer to Pages 42 for instructions on the proper disposal of medication.**

**Oxygen safety**

- Do not smoke around oxygen.
- Use caution to prevent kinks in the tubing and do not lay objects on the tubing.
- Position your system in a location that avoids heat sources or constricted areas. The area should be well-ventilated.

- No open flames should be used within five feet of oxygen equipment. Never smoke while wearing oxygen or while near oxygen equipment.
- Avoid using flammable products such as aerosol sprays, rubbing alcohol and petroleum products.
- Keep oxygen cylinders in appropriate stands and store in a well-ventilated area.
- Secure your portable tanks in the back seat of the car when traveling.

## HOME CARE BASICS

Keeping yourself and others safe from infection starts with good hand washing. Washing your hands properly and frequently is one of the best ways to prevent the spread of infection.

### Infection control in the home

- Keep the home clean and well-ventilated.
- Avoid people with colds, flu, cold sores, etc.
- Clean all patient care items after use.
- Don't clean bedpans or urinals in the sink.
- Flush all body waste and fluids down the toilet.

### Personal habits

- Wash hands with soap and water using friction for at least 20 seconds. Scrub after going to the bathroom, before preparing medications and meals.
- Take a bath as needed. Wash areas soiled with urine, stool or drainage right away.
- Cover your mouth and nose with a tissue when sneezing or coughing.
- Keep clothes and bedding clean.

- Don't share toothbrushes, towels, washcloths or underwear.
- Dry hands with paper towels or a clean, dry cloth.
- Keep fingernails clean.

#### **Food handling/preparation**

- Keep all meat and milk products in refrigerator when not being used.
- Prepare food on clean surfaces.
- Wash fruits and vegetables carefully before using.
- Cook meat well.
- Wash hands before preparing foods.
- Don't taste food with cooking spoon.
- Make sure cutting boards are cleaned thoroughly after using for raw meats.

#### **Protection of caregiver**

- Wear gloves when coming in contact with patient's body fluids.
- Wash hands after removal of gloves.
- Wash hands with soap and water before and after contact with patient-soiled body or linens.
- Put dressings and disposable materials in a plastic bag, seal it, and place it in another plastic bag.
- Keep all surfaces clean. Rinse away all soap with clean water.
- Designate a separate area for supplies. Keep all supplies out of reach of children and off the floor.
- Identify a work area that can be cleaned before and after use.
- Clean up blood or body fluids with one part chlorine bleach and 10 parts water; wear gloves for this procedure.

### Disinfection of linen in the home

- Linen soiled with body fluids is a possible source of infection.
- Soiled linen should be rinsed clean before mixing with other laundry.
- Contact of soiled linen with other surfaces should be avoided.
- DO NOT place linens on floor, if possible.
- Gloves should be worn when handling contaminated laundry. Soiled linen should be handled as little as possible.
- Soiled linens should be held away from the body and clothing.
- Wash contaminated linens separately when possible.
- Hot water, detergent, soap and bleach all aid in the destruction or removal of microorganisms.
- Tumble dry on the high setting.

CAUTION: the use of bleach may damage linen or clothing.

### EQUIPMENT:

Large leak-proof bag

Washing machine

Gloves

Detergent

Disposable apron

Household bleach

**PROCEDURE:**

1. Wear gloves when handling contaminated linen or clothing.
2. If laundry area is not adjacent to patient care area, carry soiled linen to laundry area bagged in a leak-proof bag.
3. Colorfast cotton, linen, rayon, Dacron or Orlon should be washed in hot water with one cup of household bleach added to the wash water and laundry detergent.
4. Heavily soiled linen should be soaked in a 1:10 bleach solution for 10 minutes and then laundered in an automatic washing machine.

**DISPOSAL OF MEDICAL WASTE**

If there are syringes, needles or wound dressings used in your home, special precautions are needed when discarding these items to prevent the spread of germs and to help in maintaining a healthy environment. Gloves should always be worn when handling contaminated medical waste. If a “sharps” container was given to you by the nurse to use, it can be returned to the office for disposal. If you made a sharps container by using a coffee can or bleach bottle, you can dispose of it with your household trash.

**Equipment:**

- Rigid, puncture-proof, leak-proof sealable containers such as liquid laundry soap bottles
- 1-inch tape
- Marking pen
- Heavy-grade plastic bags with ties
- Gloves



**Procedure:****1. Needles, syringes, attached tubing:**

- Locate appropriate container of suitable size and put on gloves.
- Label container, such as a coffee can or bleach bottle, using tape and marking pen with the words **INFECTIOUS MEDICAL WASTE** in large, bold print.
- Drop needle directly into open container; do not recap, bend or break the needle.
- Keep container upright throughout use.
- Close container between uses and store out of reach of children and pets.
- When container is full or will not be used again, seal the cap on with tape. **DO NOT** over-fill the container.
- Container may be discarded by disposing of it in household trash.

**2. Contaminated dressings:**

- Place soiled tissues, dressings, bandaids and gloves in plastic bag and close tightly.
- Place bag inside second bag; tie second bag securely.
- Discharge double-bagged waste in regular household trash bag.
- Use this procedure for any disposable materials that become contaminated with wound drainage or body fluids.

## CONTROLLING ODORS

Patient and caregivers feel better when the room smells clean and fresh. Sometimes simply cleaning and airing isn't enough. Commercial air fresheners may help. Here are some other ideas from our patients that may help.

- Place white vinegar or baking soda in a bowl or mug and place near the source of odor.
- Place crushed charcoal in a tray or shoebox in the room.
- Peppermint oil is especially good at neutralizing odors. Put several drops of peppermint oil on a cotton ball in an open dish.
- Potpourri can absorb odors, if the fragrance is agreeable to those in the room.
- Fans help minimize odors and make breathing feel easier.
- If odor continues, discuss additional options with your RNCM.

## BATHING AND GROOMING

The person receiving Hospice care should bathe or shower as usual, for as long as physically possible. Placing a stool or shower chair in the shower or tub may make the process easier. Ask your nurse to describe and order this equipment for you. When this is no longer possible and bathing is necessary for a person confined to bed, let that person bathe themselves as much as he or she can if they choose to maintain independence and self-confidence. Perhaps your loved one only needs you to gather bath supplies and help wash their back and feet.

If, however, your loved one is too weak, a complete bed bath can be refreshing and soothing. It is also a good way to help them conserve energy for other activities and keep the skin in good condition. Before you start:

- Gather towels, a washcloth, a light cotton flat sheet, soap, lotion and other toiletries and a basin.
- Provide as much privacy as you can during the bath, and close doors and windows to prevent drafts.

- Start by washing your hands.
- Help your loved one remove his or her nightclothes.
- Cover their body with a light blanket and wash a small area at a time to avoid chilling.
- Place the basin near the bed and **change the water as it gets cold or dirty.**
- With a wet washcloth, but without soap, gently wipe one eyelid from inner corner to outer corner, dry the eyelid, rinse the cloth and rinse and dry the other eyelid.
- Wash face, neck and ears with soap and water, rinse well and pat dry.
- Place a towel under the person's arm, and using long, smooth strokes, wipe from hand to underarm. Wash, rinse and dry completely, giving special attention to the underarm area.
- Repeat for the other arm, then place the basin on a towel on the bed, place your loved one's hands in the basin and wash and dry one hand at a time.
- Fold down the towel or blanket to expose the person's chest and stomach, and wash, rinse and dry. Be sure to dry any creases or skin folds thoroughly.
- Uncover one leg, put a towel under it, and using the same long, smooth strokes, wash, rinse and dry the leg. Re-cover that leg and repeat on the other side. Place the basin on the bed and soak, wash and dry the feet.
- Help the person turn onto his or her side, making sure he or she is not too close to the edge. Put a towel on the bed along the back, and wash, rinse and dry the neck, shoulders, back, upper thighs, and then buttocks.
- Change the water and wash the perineal, or pubic area, last. Place your loved one on the back with knees flexed and spread apart. Gently wash from front to back, away from the penis or vagina, never back and forth. Rinse well and dry gently, including the inner thighs.

- If a lotion has been prescribed to help protect the skin from irritation, this is the time to apply as instructed.
- After bathing, ask the person to turn on one side and change the blue pads and lift sheet, daily or more often as needed.

If a complete bath cannot be tolerated, give a partial bed bath. Follow all the preparation steps for a complete bed bath, but wash only face, hands, underarms and genital area, in that order.

Most patients feel better when attention is paid to their personal grooming. You can shave, brush and style the hair at bath time.

Clothing should be comfortable and as stylish as desired. If limited movement makes it difficult to get clothing on and off, cut clothing down the back and sew on Velcro or tapes.

### **MOUTH CARE**

Keeping the mouth moist and clean is important for comfort. The membranes of the mouth and the lips are very sensitive. Good mouth care may help prevent bad breath, dryness, infections, irritation and may help increase appetite and will surely increase comfort.

If you are assisting someone else with their mouth care, these tips might help:

- Raise the head of the bed to prevent choking on fluids.
- Place a dry cloth under the chin.
- Offer a sip of water to moisten the mouth.
- Use a soft toothbrush or toothette and non-abrasive toothpaste to gently brush teeth, gum and tongue.
- If teeth cannot be brushed, use a mouth rinse. Avoid mouth rinses with alcohol as that can increase soreness and cause dryness.
- Ask the person to rinse well and spit in the bowl or basin.
- Apply lubricant, such as KY Jelly, to lips every 2 hours.

**For dentures:**

- Brush or soak in denture cleaner in the morning, after meals, and at bedtime.
- Replace the dentures and check the fit. Loose dentures can cause irritation in the mouth. If dentures are causing sores, remove the dentures, then consult your RNCM and dentist.
- Sips of water, hard candy, popsicles or ice chips may relieve a dry mouth.
- If swallowing is difficult, place ice chips or frozen juices in a washcloth and ask patient to suck on the washcloth

**ALERT: If your loved one complains of a sore mouth, call Arbor Hospice or tell your nurse.**

**SKIN CARE AND PREVENTING BEDSORES**

Bedsore (commonly referred to as pressure ulcer) may develop when patients spend long hours in bed, chair or recliner without moving. They develop most frequently on the bony areas of the body such as elbows, hips, tailbone, shoulders and especially heels.

A few precautions can lessen chances that a bedsore will develop:

- Turn the person from side to side every two to four hours. Provide pain medication, if necessary, 15 to 30 minutes before turning.
- Use pillows to prop and cushion.
- Keep skin clean and moisturized.
- Keep linens clean and wrinkle-free.
- The nurse will show you how to massage around reddened areas. Don't rub reddened areas directly.

Bedsore are not necessarily a sign of poor care. As the body declines, the skin may break down despite all your efforts to prevent it.

Don't apply lotion or cream to a reddened or broken area unless it is recommended by your Hospice nurse.

**ALERT: Call Arbor Hospice if you notice a red area, a rash or if you find broken skin.**

## **YOUR LOVED ONE'S BED**

The person who is ill and the caregiver should choose the most comfortable place to sleep. The Hospice team will not insist that you change to a "hospital" bed. At some point, a special bed may become more practical; we will order one for you if desired.

### **Electric or Hospital Bed**

A hospital bed offers some practical advantages in improving comfort and making care easier. Caregivers can raise or lower the bed to provide bedside care at a comfortable and safe working height. Adjusting the height can make transfers easier and safer. The head and foot of the bed can be raised and lowered for the comfort of the person in bed. Some people choose to put the bed in the family or living room area so the person using the bed can be included in daily activities.

The nurse or hospice aide can show you ways you can make a patient's time in bed more comfortable.

### **To move someone up in bed:**

- Lift sheets (also known as draw sheets) make it easier to turn, reposition and move people who are bed-bound. A lift sheet is a flat sheet folded in half placed crosswise on the bed at mid-back and under the buttocks.
- Find someone to help. This is a 2-person job.
- If the person has a catheter bag, make sure that the tubing will not be pulled during repositioning.
- Tell the person you are caring for what you are going to do.

- Caregivers should stand across from each other on opposite sides of the bed.
- Lower the head of the bed.
- If they are able, help the person in bed bend their knees and place their feet firmly on the bed. Ask them to assist by pushing with their feet.
- Ask the person to fold their arms over their chest and tuck in their chin.
- Each of the caregivers should then role the sides of the draw sheet close to the person's sides and grasp firmly.
- When lifting, caregivers should bend knees only. Try not to bend at the waist.
- The lift sheet should be changed daily, or more often if necessary.
- A waterproof covering for the mattress can ease cleanup when a patient experiences diarrhea, vomiting, trouble controlling urine or profuse perspiration.
- Incontinence (Chux™) pads, available from a drug store, can be placed under a person in bed, making basic care easier.
- Follow all instructions for safe use of side rails.
- Padding side rails with a towel or blanket can assist during turning and daily care and can prevent injury in case of seizures.
- Your nurse or hospice aide can show you ways of changing the bed that will ease the caregiver's task and increase your loved one's comfort.
- The simple act of turning a pillow to the fresh, cool side or placing a cool washcloth on a patient's forehead can give great comfort.

## Changing Sheets

If the person you care for becomes too weak to get up safely, you may need to change the linens with them in bed. It is helpful to think of the bed in two halves. You change one half of the bed while the person lies on the other half. Then, you move them onto the clean half and change the other half.

- If they can tolerate it, remove all but one pillow and make the bed as flat as possible.
- Raise the bed to a height that is comfortable for you while you work at the bedside.
- Help the person roll to one side of the bed. Use the lift sheet if you have one on the bed. Be sure the rail on that side is up so they will not fall.
- Go to the side where you are facing his/her back. Loosen all the bedding on that side.
- Roll the soiled bedding, and tuck it under the person's hips and legs.
- Put the clean linens on that side of the bed and tuck in the top, bottom and sides. If you are using a draw sheet or incontinence pad (Chux™), place it on top of the sheet. Fold and tuck the clean linen underneath the roll of linen you are removing.
- Pull up the side rail on the side you've been working from and help the person roll over the roll of linen onto the clean side of the bed.
- Move around to the other side of the bed, lower the rails and pull out the dirty linen.
- Unroll the clean linen and tuck in.
- Reposition the person comfortably and cover with linens.



## Changing a disposable brief or pads on someone in bed

Gather supplies:

- Latex, or other protective gloves
- Incontinence pads (Chux™)
- Disposable briefs
- Clean linen, if needed
- Wash basin
- Cleaning supplies or pre-moistened wipes
- Change soiled briefs, pads or linens promptly to prevent skin breakdown.
- Explain to the person you're caring for what you are going to do.

Cover chest with a sheet and unfasten brief tabs, roll the person onto one side. If the person is in an adjustable hospital bed, raise the side rail on the side away from you. The person can use the rail to help them roll to the side and hold themselves steady.

- Remove soiled materials and clean area with a mild soap and warm water.
- Apply barrier ointment or cream, if needed.
- Place clean sheet, pad and/or brief underneath the hip area, roll the person back onto the clean linen and fasten brief.

## ACTIVITY

Loss of control is one of the biggest frustrations of illness. Physical and mental activity promotes independence, one of the goals of Hospice care.

Your loved one may desire to get out of bed, if possible, and walk a bit or sit in a chair.

Many patients remain alert and mentally active, even if physical activity is limited. They can play cards or board games, have someone read to them or listen to books on tape.

Talk to your loved one about family plans and activities. Include the person in the discussions and in decision-making as much as possible.

If your loved one has trouble moving but wants to get out of bed, have another person help you with the transfer to a chair. Don't do it alone. Your nurse will show you how to lift and move.

Even if your loved one is bed-bound, you can exercise the arms and legs as long as this movement does not cause pain. Please discuss which exercises will be most beneficial to your loved one with the nurse.

People who are limited in physical activity often like to watch television, even if they never enjoyed it before, because it is a link to the outside world.

## USING A CANE OR WALKER

- When a person is using a cane, walk on the side opposite the cane. The cane should be used on the side of the weak leg.
- When a person is using a walker, walk behind them for support.
- Make sure the walker is placed within their reach when you leave.
- Remind them not to grab the walker arm to help them get up from a chair; the walker may tip over. They should always push themselves up from the chair using the chair arms and shift their hands over to the walker rails before standing up.

## HOW TO ASSIST WITH TRANSFERS

### Using Body Mechanics

Using the body in an efficient and careful way is known as body mechanics. Body mechanics involves using good posture, balance and the strongest and largest muscles of the body to perform work. Fatigue, muscle strain and injury can result from improper use and positioning of the body during activity or rest. You need to be concerned with both your own body mechanics and that of your loved one.

Posture or body alignment is the way in which the body parts are aligned with one another. Using good body alignment (posture) allows the body parts to move and function with strength and efficiency. Good alignment is necessary when standing, sitting or lying down.

You need a good base of support to maintain balance. Stand with both feet apart so that you will have a wide base of support. This will provide more balance and stability as you work with your loved one.

The strongest and largest muscle groups are located in the shoulders, upper arms, hips and thighs. You should use these muscles to lift and move heavy objects. If you use smaller and weaker muscle groups, you place strain and exertion on them causing fatigue and injury. You can use the strong muscles of your thighs and hips by bending your knees or squatting to lift a heavy object. You should avoid bending over from the waist when lifting. Bending from the waist involves the small muscles of the back. When you hold objects close to your body and base of support you are using upper arm and shoulder muscles. If you hold the object away from your body, you exert strain on the smaller muscles of the lower arms.

## General rules

You should use good body mechanics in everyday activities. Cleaning, doing laundry, getting in and out of a car, picking up a baby, mowing the lawn and shoveling snow are some activities that require good body mechanics. The following rules will help you use good body mechanics for safe and efficient functioning when lifting and moving your loved one and heavy objects.

1. Make sure your body is in good alignment and that you have a wide base of support.
2. Use the stronger and larger muscles of your body. These are located in the shoulders, upper arms, thighs and hips.
3. Keep objects close to your body when lifting, moving or carrying them.
4. Avoid unnecessary bending and reaching. If possible, have the heights of the bed and overbed table even with your waist when giving care. You can adjust the bed and table to the proper height.
5. Face the direction in which you are working to prevent unnecessary twisting.
6. Push, slide or pull heavy objects whenever possible rather than lifting them.
7. Use both of your hands and arms when lifting, moving or carrying heavy objects.
8. Turn your whole body when you change the direction of your movement.
9. Work with smooth and even movements. Avoid sudden or jerky motions.
10. Get help from someone else to move heavy objects or an ill person whenever necessary.
11. Squat to lift heavy objects from the floor. Push against the strong muscles of your hips and thighs to raise yourself to a standing position.

## Step-by-step directions for transfers

When positioning your loved one or transferring them from bed to chair, always allow them to assist as much as possible.

1. Talk to your loved one to determine his or her abilities. Consider their weight, changes in their condition and the distance you need to transfer them. Know your abilities and always ask for assistance if it is available.
2. When moving a patient, observe their color and facial expression. You should not help a person up if you notice they suddenly seem pale, if they are perspiring excessively, or if they tell you they feel dizzy, faint, too weak or too tired.
3. Prepare to transfer the person who is ill by putting slippers on them or moving the equipment into position. Explain to your loved one what you are doing before you do it and as you do it. Don't forget to lock the wheelchair or any equipment with wheels. Adjust the footrests on the wheelchair to support their legs.
4. If the person is using a hospital bed, raise the head of the bed to sitting position. (Be careful to collect catheters or any other drainage appliances.) While supporting your loved one, slide his or her legs off the edge of the bed and let them dangle. Assist the patient into sitting position on the side of the bed. Make sure the bed is in its lowest position to allow the patients's feet to rest flat on the floor. Pause and wait a minute because your loved one may experience dizziness at this time.
5. Scoot your loved one forward so feet are touching the floor. Place your arms under theirs, grasping around their back. Allow the person to grasp your shoulders or arms. **NEVER ALLOW the PATIENT TO GRASP AROUND YOUR NECK.**

6. Position yourself as close to the bed as possible. Hold your head and back in a straight line, tighten your abdominal muscles and bend your knees. Place the inside of your knees against the outside of the knees of your loved one to allow stability as he or she stands. Gently rock the person and lift to standing position on the count of three, using your leg, buttock and abdominal muscles. Don't forget to talk them through each action as you do it.
7. Pivot-turn your loved one, taking small steps to turn in place. Avoid twisting your back or trunk. Lower gently into the chair or bedside commode. Be sure she or he is seated securely, with their hips all the way back in the seat before you release your hold.

If your loved one should fall and is unable to get up, call Arbor Hospice for instructions. Provide a pillow and blanket for the patient's comfort until help arrives.

### **MEALS AND SNACKS: IT'S NOT *HOW MUCH* THAT COUNTS**

Food meets both physical and social needs. Even if the Hospice patient doesn't eat a lot at meals, the time together with family and friends may be more important than the food. It isn't necessary to eat to participate in the social interaction of a meal.

A progressive loss of appetite is a common part of decline. As the body's systems slow, the need for caloric intake diminishes. Food that has fueled healing in the past may now bring about discomfort and possibly pain. Eating and drinking no longer brings pleasure and renewed energy. Foods may not taste right.

Think about how much work it is for the body to process food. The ability to digest food and maintain the proper balance of fluid is lost as the body shuts down. Lack of interest in eating and drinking may be a way for the body to protect itself from taking in something that could cause distress.

Food and drink cannot undo what is happening. Listen to what the patient wants. Focus on what brings them pleasure.

Respect the changes the body is signaling. Pressuring someone to eat or drink when they do not feel up to it will not make anyone feel better.

- Offer small amounts of preferred foods. Cool, soft foods like applesauce or pudding are often most appealing.
- Offer sips of water or ice chips.
- Provide frequent mouth care.
- Moisturize the lips. Use water-based or lanolin-based lubricants or moisturizers rather than petroleum-based products due to concerns about infection or flammability.
- Talk to your care team about your concerns and ask any questions you have about artificial nutrition and hydration.
- Serve meals when your loved one is most likely to be free of pain and have the most energy. Breakfast is often the best meal, no matter what time of day it is eaten.
- If you would like to discuss diet or eating concerns, contact your RNCM who can assess the need for a dietitian consult.

## **MAKING EATING EASIER**

### **When your loved one needs help with eating and drinking**

There are several ways to help your loved one remain more independent with eating. Ask your nurse for information on the following:

- Overbed tables
- Modified cups
- Special utensils
- Towels as bibs

**If your loved one has trouble recognizing things:**

- Name each food
- State whether the food is hot or cold

**To feed a patient who wants to eat but can no longer use a fork or spoon:**

- Position the patient into a sitting position or as close to upright as possible.
- Offer small bites, seasoned as desired.
- It is preferable to use a spoon when feeding your loved one. Fill the spoon only half full.
- Make sure each bite is swallowed before you offer more.
- Consider offering finger foods that the patient can easily pick up.
- Have a napkin, towel or bib handy to help keep your loved one clean.
- Alternate between liquids and solids.
- Follow your loved one's suggestions and requests.
- Do not force your loved one to eat.

**To help your loved one drink:**

- Support the head and allow the person to guide the cup.
- Use a bendable straw, which you can cut in half if drawing liquids is difficult.

If chewing or swallowing are difficult, offer soft foods. For someone who is nauseated or in pain, offer liquids rather than solid food. Cooler foods are usually easier to keep down.

**ALERT: Stop feeding and call Arbor Hospice if you notice increased coughing, choking or congested breathing while eating.**



## Decline in eating

Your loved one may have a decrease in appetite and thirst, wanting little or no food or water. In time, food loses its importance to a dying person. It may begin with a distaste for certain foods – often meat and vegetables. Then it may be a preference for soft textures, like cereals, soups, milkshakes and puddings. The amount of food eaten declines and energy levels weaken until only sips of fluids are taken from time-to-time.

Families may believe that a lack of eating is causing the patient's decline. They assume that, if only the patient would eat more, the patient would be stronger. But at some point, food cannot prolong life, control symptoms or provide comfort.

It may be difficult to accept that the weakness and fatigue are caused by the final stages of the terminal disease. The emotional impact of watching a loved one decline can cause anxiety, frustration and conflict within the family. But constantly telling a patient to eat or drink will only increase tensions and may cause the patient to feel angry or depressed and become more withdrawn. Many patients experience nausea and abdominal discomfort when they eat in order to please others.

If there are frustrations about poor eating, it is better for the family to share them with the hospice staff rather than to confront the patient. This is the time to spare the patient from emotional struggles and shelter them in compassion. Ask your hospice nurse to contact the consulting dietitian if you seek nutrition advice.

## BOWEL MOVEMENTS

People's bowel habits vary. Some may have a bowel movement every day, or even several times a day, while others may go two or three days between bowel movements.

Using a bedpan or commode:

- Pad the back portion of a bedpan and/or sprinkle cornstarch on the edges to prevent sticking.
- A small amount of water or a plastic bag liner in the commode bucket or toilet paper in the bottom of a bedpan can aid cleanup.

Always wash your hands and the patient's hands after assisting them with toileting.

If your loved one is concerned about bowel problems, discuss it with your nurse. The nurse will ask the doctor about the use of stool softener or laxative.

## Part 4: Symptom Management

### **PAIN MANAGEMENT**

Your comfort is our priority. There are many ways to prevent and manage symptoms effectively. Reducing pain leads to easier breathing, better sleep, reduced anxiety, increased interest in daily activities and mobility. You don't need to suffer.

#### **Medications**

Your Arbor Hospice nurse will consult with your physician on the first visit and obtain a list of all the medications your loved one needs.

The RNCM will teach you about the medications, why they are being given and what possible side effects they might have.

It will be easier for you to help the patient take all the prescribed medications if you keep a written record. You will be provided with a form that other families have found useful. Listing the medications given and their accompanying side effects will help your physician determine if they are effective or need to be changed.

One of the most important things you can do to help manage pain is talk about it. You are the expert on how you are feeling. Your Arbor Hospice care team members need and want you to tell them when pain is happening, how bad it is, and what it feels like. Your care team will ask many questions about your pain because this information is very important in determining:

- What type of pain you are having?
- What treatments will be most effective?
- Where is the pain? Pain can be in more than one place. Let your health care team know of all the painful areas.
- Which site of pain is the most severe or bothersome?

PART  
**4**

- What does the pain feel like? Your description of the pain is very important in helping your care team decide which medications or treatments would work best.
- Which of the following words describe your pain?
  - Aching/Searing/Stinging
  - Burning/Sharp/Tearing
  - Cramping/Shooting/Throbbing
  - Cutting/Squeezing/Tingling
  - Crushing/Stabbing
- How intense is the pain? A number scale is frequently used to rate pain. The scale most often used is a 0-10 scale, with 0 being no pain, and 10 being the worst pain you can imagine. You can also describe pain with words like none, mild, moderate, severe or worst possible pain. Patients may not be able to express scores verbally.

### Typical pain scale used by Arbor Hospice



### Non-medical approaches to managing pain

As a caregiver, you may also be able to assist your loved one in finding some relief from pain caused by illness.

Other methods for assessing pain include:

- Observing the patient for non-verbal indicators of pain.
- Changes in breathing: Patient may appear to be experiencing labored breathing, hyperventilation, or irregular breathing
- Moaning, groaning, crying or repeated calling out in a troubled manner.

- Having a sad, frightened, frown or grimace appearance on their face.
- Appears tense, fidgeting, pacing, clenched fists, knees pulled up, pulling or pushing away or striking out.
- Difficulty in consoling or providing comfort to the patient.

### **Pain control**

Arbor Hospice staff will ask the question, “Are you satisfied with your pain control?” We will work with you until you are satisfied. This helps your team know how well your treatment plan is working and what changes need to be made.

Some important information about pain control:

- Take prescribed medication as directed.
- Take prescribed medication on schedule, rather than waiting until you are in pain. This is how pain is prevented. Waiting until the pain is “bad enough” can make pain harder to control.
- All pain medications have side effects of nausea, constipation and drowsiness. You may have trouble concentrating. Be sure to report any side effects to your nurse or call hospice and speak with the RNCM. Some side effects are temporary, some last longer. Almost all of them can be prevented with other medications. Be sure to take any medications prescribed to treat the side effects. It’s important to continue the pain medication or bowel regimen as prescribed. If you have concerns or questions, please discuss with your RNCM.
- Discuss goals and side effects with your nurse. Each time the nurse visits, he or she will talk with you about your level of pain control to evaluate the effectiveness of your plan of care. This is the time to give an honest “yes” or “no” answer. The goal is to have pain relief and comfort.
- Be sure to notify your RNCM if you have less than a three-day supply of medication.

**ALERT: If the medication is not working, or you are experiencing side effects, call Arbor Hospice.**

**ALERT: If pain increases in spite of prescribed medications, call Arbor Hospice immediately. Don't wait until morning. Don't wait until it gets "bad."**

## **PROPER DISPOSAL AND DESTRUCTION OF MEDICATIONS**

Once medications are dispensed to our patients, those medications become the lawful possession of that patient. There may be times when there are unused or unwanted medications that require disposal. For patients who reside in facilities, the facility will follow their internal policies to destroy or dispose of medications. But for patients who reside in their own homes, it becomes the responsibility of the patient or members of the patient's household to properly dispose of unused medications. Arbor Hospice staff shall never take possession of or transport medications that were dispensed to our patients for the purpose of destruction or disposal.

Arbor Hospice staff will provide education and information about proper medication disposal and destruction including:

- 1) In-home disposal and destruction methods
- 2) Drug take-back events: Scheduled events through local law enforcement or city/county government
- 3) Mail-back programs: Conducted through manufacturers, distributors, narcotic treatment programs, hospitals/clinics, and retail pharmacies
- 4) Collection receptacles: Provided by law enforcement agencies, hospitals, clinics, retail pharmacies.

Hospice patients and/or their families may find authorized collectors in their communities by calling the Drug Enforcement Agency Office of Diversion Control Registration Call Center at 800-882-9539. Additional information on the disposal of medication can also be found on the Food and Drug Administration website: [www.fda.gov/consumer](http://www.fda.gov/consumer)

## **Myths about morphine (Roxanol, MSIR, MS Elixir, Oramorph, MS Contin)**

Morphine is one of the best pain control medications. Unfortunately, many people refuse morphine because of incorrect information. If your physician suggests morphine for pain control, please discuss any concerns you may have, and these “morphine myths,” with your Hospice nurse.

### **The Myths of Morphine**

*MYTH: If I take morphine now, there won't be anything strong enough when I really need it.*

**FACT: If you are in pain now, you need the medication now. The dosage can be adjusted later, as necessary. Sometimes other medication is added to help achieve pain relief.**

*MYTH: I may stop breathing.*

**FACT: Your physician will not prescribe doses high enough to stop breathing.**

*MYTH: I will become addicted.*

**FACT: People who take morphine for physical pain almost never become addicted.**

*MYTH: Morphine needs to be injected. Morphine won't work if taken by mouth.*

**FACT: Arbor Hospice has achieved excellent pain relief using oral morphine.**

*MYTH: There is a limit on how much the doctor can prescribe.*

**FACT: There is no limit on the amount of morphine a physician can prescribe to relieve pain.**

*MYTH: It's only used when death is imminent.*

**FACT: Many patients take morphine for six months or more.**

*MYTH: I will experience a “high” just like an addict.*

**FACT: People who take morphine to control pain do not experience a drug “high.”**

*MYTH: I am allergic to morphine. The last time I was given morphine, I threw up.*

**FACT: Nausea is a side effect. It is not an allergy. Actually only about 30% of people get nauseated. Nausea can be managed.**

## **NAUSEA AND VOMITING**

Medications, constipation, disease or other factors may cause a patient to become nauseated and vomit. This can be distressing to both patient and family. If the patient feels nauseated or is having episodes of vomiting, please notify Arbor Hospice.

### **THE FOLLOWING COMFORT MEASURES MAY HELP:**

#### **Managing nausea**

- Provide good ventilation and reduce strong odors.
- Eat small, frequent meals, resting in an upright position after each meal.
- Eat foods at room temperature or cooler. Hot foods may trigger nausea.
- Suck on ice chips or take frequent sips of a liquid such as ginger ale.
- Avoid drinking liquids with meals.
- Try relaxation techniques such as deep, controlled breathing.

#### **Managing Vomiting**

- Keep a bowl or emesis basin near the bed.
- If lying down, turn head to the side to prevent choking.
- After vomiting, rinse the mouth with water, brush teeth and/or rinse the mouth with a mouth rinse.
- Place a damp, cool cloth on forehead, neck and wrists.
- Do not eat or drink anything until the vomiting has stopped.
- When the vomiting episode has passed, take liquids slowly. Start with sips and gradually increase to 1/4 cup every 15 minutes. Water, soda pop, juice, broth, tea and diluted sports drinks like Gatorade™ can be used.
- Ask Arbor Hospice about specific medications to help nausea and vomiting.



**ALERT: If your loved one vomits more than once in an 8-hour period, call Arbor Hospice.**

## **BREATHING PROBLEMS**

As a person becomes weaker, the normal process of breathing in and out becomes more difficult. This is referred to as “shortness of breath.” The person may experience rapid or noisy breathing, or may feel winded. This can occur with activity, or even during rest. If shortness of breath comes on suddenly or is causing distress, please call Arbor Hospice immediately.

### **SOME WAYS TO EASE SHORTNESS OF BREATH WITHOUT MEDICATIONS:**

Your Arbor Hospice care team wants to help your loved one breathe as comfortably as possible.

- Provide calm reassurance.
- Raise the head of the bed or place pillows behind the head, neck and shoulders.
- Use a cool-mist humidifier in the room, especially in the winter.
- Eliminate allergens such as smoke, dust and mold.
- Keep the room cool.
- Certain positions can help with chest expansion. Sitting upright and leaning forward helps air to move in and out of the lungs. Breathing while lying on one side may be easier than lying on the other side.
- Conserve energy. Rearrange the environment to reduce exertion. For example, place bedside commode next to chair or bed.
- Plan activities to conserve energy. Schedule activities to include rest time. For example, eat first, then rest, and then bathe.
- Try to conserve energy to do those things that are enjoyable. For example, let someone assist with dressing and bathing so you feel up to do more pleasant activities.

- Try relaxation techniques, music and visualization.
- Be sure clothing around neck and chest is loose and light-weight.
- Run a fan at low speed to move air in the room; be sure it doesn't blow directly on the person who is ill.
- If possible, use an air conditioner in hot humid weather.
- Crack the window open.

## **BREATHING PATTERN CHANGES**

There are many different ways to help decrease feelings of shortness of breath. While some patients may need medication, others may receive benefit from oxygen therapy. Similarly, not everyone needs or will benefit from using oxygen.

## **WEAKNESS AND FATIGUE**

Weakness and lack of energy are common complaints with most serious illnesses. There are many things you can do to manage these symptoms.

- Schedule rest periods between activities.
- Create an environment that helps you sleep well at night.
- Eat small, frequent meals throughout the day.
- Focus energy on activities that are important to you. Consider saving energy by letting a hospice aide assist with hygiene, bathing and dressing.
- Avoid activities such as driving, cooking and handling machinery when drowsy or dizzy.

Sometimes the normal sleep-wake cycle is reversed: the person is awake at night and asleep during the day. Your loved one may spend an increasing amount of time sleeping. This is a normal bodily process, caused by changes in the disease progression. For those who take pain medication, they may feel drowsy or sleepy when they first take the medicine. Sometimes, if there has been a period of prolonged pain, once relieved the patient's sleep may improve. If you have concerns, talk to your Hospice team.

## LOSS OF BLADDER AND BOWEL CONTROL

Incontinence is the inability to control urination and/or bowel movements. Managing incontinence can prevent discomfort, skin problems and possible infections. If your loved one is aware of the occurrences of incontinence, it may be disturbing to them. Reassure the person and ask the Hospice staff to show you ways to make your loved one more comfortable and help you get the supplies and equipment you need.

To help manage episodes of incontinence, you can:

- Routinely offer assistance in getting to the bathroom.
- Ask the person if they need to use the urinal, bedside commode or bedpan every few hours. Keep these items close by.
- Use disposable briefs, pads, shields and/or protective bed pads to contain body waste.
- Check for wetness every couple of hours.
- Change soiled briefs, pads and liners as soon as possible to prevent skin irritation and breakdown.
- Clean the genital area with soap and water after each episode. Gently dry well. A barrier cream will help protect skin.
- If taking diuretics to increase urine output, ask your nurse or physician about scheduling them early in the day to prevent the need to urinate frequently during the night.
- Ask your nurse about ordering a bedside commode.

## PROBLEMS WITH URINATION

Some patients lose their ability to control urination. Others are unable to urinate.

### **ALERT: Call Arbor Hospice if the patient:**

- has been unable to urinate for 12 to 15 hours
- has lower abdominal pain

If it is determined that the placement of a catheter is appropriate, the nurse will place it and provide instructions for its use.

**NOTE: The placement of a catheter increases the risk of infection. Therefore, it should be used cautiously,**

### **CARE OF A URINARY BLADDER CATHETER:**

- A urinary catheter drains urine continuously from the bladder through a plastic tube and into a collection bag. The catheter is held inside the bladder by a small balloon filled with sterile saline. The catheter eliminates the need to use a bedpan or toilet for urination, but a bedpan is still needed for a bowel movement. The following tips may provide comfort and help to prevent bladder infections:
- Wash your hands with soap and water before and after handling the catheter, tube or bag.
- Keep the bag below the level of the bladder at all times.
- Check to be sure that there are no kinks or loops in the tubing and that the person is not lying on the tubing.
- The urine drainage bag should not be placed directly on the floor. If this is not possible, the bag should be placed on clean newspaper or other clean barrier.
- Do not pull or tug on the catheter tubing.
- Wash around the catheter entry site with soap and water twice each day and after each bowel movement.

## URINE DECREASE

As death nears, a person's urine output normally decreases and may become tea colored (concentrated urine). This is due to decreased fluid intake as well as decreased circulation of blood through the kidneys. Near the end, urine production may decrease even more or stop completely.

## DIARRHEA

Diarrhea is characterized by frequent, watery stools. A person with diarrhea may also have crampy abdominal pain. Keep a record of the number of stools on the page provided. Record date and time.

**ALERT: Call the Arbor Hospice nurse if the person who is ill has two liquid stools within an 8-hour period.**

The physician may prescribe medication or suggest a non-prescription remedy to treat diarrhea. Do not use any medication to treat diarrhea before discussing the situation with your Hospice nurse.

When caring for a person with diarrhea:

- If a medication is used, give only according to directions. Overuse may cause constipation.
- Medications may make a person thirsty. Give as much fluid as he or she wants.
- Give only clear liquids (no milk or milk products) until the diarrhea stops.

What is a "clear liquid?" Put the liquid in a clear glass. If you can read a newspaper through the liquid, it is okay. Good choices are apple juice, ginger ale, Sprite or Jell-O water.

- After each loose stool, wash the rectal area from front-to-back only with mild soap and water. Apply a lotion recommended by your nurse.
- If your loved one can't get to the bathroom or a commode, keep a bedpan close by.

Place a waterproof pad under the person in bed. That way, if leakage occurs, you may not have to change all the bed linens.

## **CONSTIPATION**

Constipation is a symptom that your care team takes very seriously. Changes in bowel function are common during illness. Many factors can lead to slowed bowel function and hard, infrequent stools. Don't be embarrassed to talk with your care team about this problem – it can be treated. If your loved one is experiencing constipation or taking medications that can lead to constipation, your care team will work with you to create a plan.

Other causes of constipation can include changes in diet, particularly low fiber and a lack of fluids, decreased activity and changes in the intestinal lining or mobility.

To help relieve constipation:

- Talk openly with your nurse about any current or past problems with the patient's bowels.
- Tell your nurse what has worked – and what hasn't worked – in the past.
- Offer water, juice and other liquids as the patient is able to tolerate.
- Be sure to follow the prescribed bowel regimen.
- Keep track of the frequency of bowel movements.
- Try to have your loved one sit upright on the toilet, commode or bedpan for a period of time at the same time each day (usually after breakfast or whatever time he or she usually has a bowel movement).
- Offer warm fluids at this time.
- If possible, maintain privacy by placing a screen around the bed or commode.



Many medications, especially those for pain, cause constipation. If your physician prescribes a pain medication, be sure to follow the physician's instructions for taking laxatives or stool softeners along with the pain medication. Bowel medications are usually to be taken regularly, not on an as-needed basis. Bowel medications are prescribed to prevent constipation. Don't stop the pain medication, laxative or stool softener unless instructed to do so by your nurse or physician.

**ALERT: Unresolved constipation can lead to nausea and vomiting.**

**ALERT: Tell your nurse or call Arbor Hospice if your loved one has not had a bowel movement in three days.**

## **ANXIETY AND CONFUSION**

Hospice patients can become anxious or confused for a variety of reasons. It is important for the caregiver to remain calm while trying to determine the cause of the anxiety or confusion.

### **CONFUSION/DISORIENTATION**

Your loved one may seem confused about the time, place and identity of people nearby, including close and familiar people. This may be due in part to metabolic changes. Identify yourself by name so the person doesn't have to guess who you are. Speak softly, clearly and truthfully when you need to communicate something for the person's comfort. For example, "It's time to take your medication. I'm going to put it in your mouth now." Explain the reason for the medication, for example, "so you don't begin to hurt."

Avoid quizzing the person on details such as time and place. This may cause increased anxiety, frustration and confusion.

Your loved one may be comforted by the presence of a familiar person at night, when restlessness and anxiety are sometimes magnified.



## **SOME COMMON REASONS FOR CONFUSION:**

- Infection (Examples: urinary tract or respiratory)
- Medications (NOTE: Medications may need to be re-evaluated by Arbor Hospice)
- Brain metastases (spread of tumor to the brain)
- Change in daily routine
- Decreased oxygen to brain
- Progression of the disease
- Terminal confusion in the final hours, days or weeks of life

If you notice gradually increasing confusion or anxiety, call Arbor Hospice or discuss your observations with the nurse during a routine visit.

## **THESE SIMPLE STEPS MAY PREVENT THE CONFUSION FROM BECOMING A SOURCE OF IRRITATION BETWEEN PATIENT AND FAMILY:**

- Keep a calendar and clock in plain view so that the person who is ill can see the date and time rather than asking frequently.
- Remind the person of the date, time and other facts, including names of visitors and caregivers.
- Ask questions or make statements one at a time. Wait for slow responses.
- Be patient with your loved one. Communication becomes more challenging with increased weakness, fatigue, disease progression and increased stress.

## **RESTLESSNESS/HALLUCINATIONS**

Your loved one may make restless and repetitive motions, such as pulling at the bed linens or clothing, or may pick at the air, as if something were flying around. Do not attempt to interfere or restrain such motions. Instead, speak in a calm, soothing manner.

Restlessness may also come if unresolved or unfinished business prevents the patient from letting go. Your Hospice team includes specially-trained professionals who can evaluate what is happening and help you find ways to help the person achieve peace. Reminiscing, reading comforting passages, playing music and reassuring the person can promote increased peacefulness.

Medications may also reduce anxiety, confusion and restlessness. Your physician may recommend medications to help calm your loved one.

**ALERT: If there is a sudden onset of confusion or anxiety, call Arbor Hospice immediately.**

## **SEIZURES**

Patients with brain tumors or tumors that have spread to the brain may have seizures. Most seizures stop by themselves. The person having the seizure is unaware of it, but the events are often upsetting to observers. The main goal during a seizure is to protect the person from any injury.

### **If your loved one has a seizure:**

- Help the person lie down, either in bed or on the floor, whichever is easier or safer at the time. Move furniture or objects out of the way.
- Turn the head to the side to keep the airway open, but don't try to force anything into the mouth.
- Don't restrain the arms or legs.
- Sit quietly with the person. People are frequently sleepy or dazed following a seizure.
- Call Arbor Hospice as soon as possible and report the seizure.

### **If the person has frequent seizures:**

- Have the nurse show you how to pad side rails of the bed or the wall next to the bed with pillows or blankets.

- Medications can be used to control seizures. If medications are prescribed, be sure you know how and when to give them.
- Seizure medications may cause rashes, reduced muscle coordination and sleepiness. If you see these symptoms, call Hospice.

**ALERT: If your loved one has a sudden seizure, call Arbor Hospice.**

## **FEVER OR CHILLS**

Fever is a temperature greater than 100.5° by mouth, 99.5° by rectum or 101.5° by armpit. Fever may be accompanied by sweating, rapid heart rate and breathing, or chills and confusion.

Before calling Arbor Hospice, you may want to take note of the following indicators which will be helpful in assessing the patient's needs:

- Take the patient's temperature.
- Is the fever new or an ongoing problem?
- Is there a pattern of fever every afternoon and evening?
- Are there night sweats?
- Is the person coughing or short of breath?
- Is there pain with urination, or cloudy or smelly urine?
- Are there draining wounds or bed sores?
- Is anyone else in the home ill? Was there an ill visitor?
- Is there a sore throat or earache?
- Has the person recently had chemotherapy or a blood transfusion or a change in medication?
- Has there been a decrease in urine, change in pulse or breathing?

## **THE FOLLOWING COMFORT MEASURES MAY HELP:**

- A cool wash cloth on the forehead
- Place ice packs wrapped in towels in armpits and groin
- Regular turning
- Fresh, dry bedding
- Ice chips, as desired
- Light blankets

Talk to your Arbor Hospice team about medications to help promote comfort.

### **BLEEDING**

Exterior tumors or sores may bleed. Bleeding isn't usually painful, but it can be frightening for everyone. A calm, reassuring attitude will reduce the fears of a person who is bleeding. Normally, bleeding stops in five to six minutes after local pressure is applied to the skin.

If there is a possibility of bleeding, keep a small stack of dark-colored towels at the bedside, along with a plastic sheet or bag. The towels will help stop the blood flow, and the plastic will protect the bedding. Dark towels make the redness of blood less apparent and help calm both the patient and anxious family members.

- In case of bleeding from the skin, apply pressure locally in the area of bleeding.
- In case of bleeding from nose or mouth, turn the person on one side.
- For a nosebleed, gently pinch the nostrils together or use clean gauze to pack the nostrils. An ice pack placed above the nose may help stop the bleeding.
- After a nosebleed or bleeding from the mouth, help rinse the person's mouth.

In rare cases, patients may cough up blood, vomit blood or pass blood from the rectum. This can be because of specific tumors in the lungs or gut or because of normal disease progression. This kind of bleeding can cause anxiety to the patient or family. If this occurs, call Arbor Hospice.

### **SOME SIMPLE THINGS YOU CAN DO:**

- Put on protective gloves.
- If blood is coughed up, help clear the phlegm and blood from the person's mouth. The person should sit upright or in a semi-sitting position or lie on one side in bed.
- If blood is vomited, do the same things as above. Additionally, give prescribed medication for nausea or vomiting.
- If blood is passed through the rectum, keep the area clean as you would after bowel movements.

**ALERT: If you are unable to control bleeding, or the amount of blood loss concerns you, call Arbor Hospice.**



## Part 5: The Final Days

Arbor Hospice staff realize this is one of the most difficult and challenging periods you and your family will experience. We understand and support your need to know what is happening in this journey at the end of life.

Dying is something we all will do, yet most of us have had little experience with the realities of end-stage illness and death. Death can come suddenly, but more often, death comes after a time in which there is a natural slowing down of the body's physical and mental systems. Thinking of dying as a process can help you better understand the changes as they take place. This process is different for each individual and may last from hours to days, weeks, and even months.

This section offers helpful information about:

- Changes that take place during the dying process.
- What you as loved ones, family members, and caregivers can do to help.
- What happens at the time of death.
- What to do at the time of death.

As the body's systems slow down and functions less efficiently, you will notice many changes. It may help to remember that dying is not like you may have seen on TV or in the movies. In reality, people look different from how they looked when they were healthy. They may talk or make noises, move around, feel confused or disoriented, have times when they are unresponsive and times when they are more alert, and will depend on others to meet some – if not all – of their personal care needs.

These changes are natural. They may not be neat and tidy, but this time can still offer opportunities for dignity, love and respect.

## **EMOTIONAL CHANGES**

### **Sadness and disappointment**

Your loved one may be saddened and disappointed to realize that their life will end before they have the opportunity to enjoy relationships or complete their life goals. This feeling is especially likely to occur in younger people.

### **Fear**

There is much about dying and death that is a mystery. Fear is normal as we try to understand and come to terms with what is happening. It is OK to let others know that you are afraid. In sharing this feeling we can find answers, reassurance and hope.

### **Separation and withdrawal**

In the last months, weeks and days of life, it is common to begin to focus more inwardly. It is common to begin sleeping more, talking less and losing interest in things that had previously been enjoyed. For example, the person may not want to watch a favorite TV show, visit with a neighbor, or take care of a favorite pet.



As death nears, your loved one may seem unresponsive or in a comatose state. Since the ability to hear usually isn't altered in the process of dying, continue to speak to your loved one in your normal tone of voice. Identify yourself by your name when you speak; hold the person's hand and say whatever you need to say for your own sake and to help the person let go.

Your loved one may accept when death is near. It may take more time for family and friends to reach the same state of acceptance.

Social work and spiritual care team members are available to provide support at any time. Some important words may include:

I love you.

I'll miss you.

I know you are tired.

I will be OK.

It's all right for you to go.

### **Loss of independence and relationships**

People who are ill often believe they are a burden to their loved ones. In frustration, they may become angry and lash out at those who are closest. The impact of this anger on a tired and anxious caregiver can be devastating. As with all anger, remind yourself that stepping back and allowing "breathing space" gives everyone a chance to assess what is happening.

The loss of independence and privacy can leave everyone feeling particularly vulnerable. Personal dignity and well-being matter greatly. Everyone has their own ways of handling these changes and their own limitations. Your care team will help you anticipate and adjust to the changes that come with the final stages of illness.

### A Hospice Physician's Experience

In my experience, patients respond uniformly to the following question with an emphatic "No."

**QUESTION:** *If your wife/husband/child/best friend were the patient, would you consider it a burden to take care of them?*

When the patient says, "No, of course not," it allows the caregiver and family to tell the patient that they do not consider it a burden, either.

Also, it is important for patients to know that families need to provide care. It helps them cope. It helps them prepare for death, separation and saying goodbye. It is an act of love and an honor to care for loved ones. It is equally an act of love and an honor to allow others to care for us.

You may find it helpful to:

- Encourage as much independence as possible.
- Promote dignity by maintaining privacy.
- Talk about something else while providing personal care, reminisce, share your loving feelings, or find something to laugh about.
- Share your concerns and limitations openly with your care team.
- Be patient with yourself - what feels awkward at first can get easier with practice.
- Cherish this chance to honor the person you care about by showing your love, compassion and commitment.
- Accept help as it is offered and plan to reach out to friends, family and your hospice care team for additional help.

## PHYSICAL CHANGES

As illness makes the body less able to function normally, you may notice some or all of the following signs. There is no way to know how long this process will last. Everyone is different. Know that you can call your care team at any time of day or night if you have a question or concern.

### Changes in pain

The amount of pain and the awareness of pain can fluctuate as death approaches. Pain medications can be adjusted to help you be as aware and alert as you would like while maintaining a level of comfort that is acceptable to you.

### Loss of appetite

Again, a progressive loss of appetite is a common part of the dying process. (Please refer to page 37 in Section 3 for more details.) If this is hard for you as a family member, friend or caregiver to accept, you are not alone. It might help to keep in mind that the person you care for is dying because of their illness, not because they do not feel like eating.

### Changes in bowel and bladder function

Advancing illness affects the body's ability to process food and fluids and to eliminate waste products. These changes are often the ones people are least comfortable talking about and raise real concerns about dignity and caregiving. Constipation is common. Urine may decrease and turn darker and smell stronger as food and fluid intake naturally decreases. Disposable pads, briefs or a catheter may be needed to help with incontinence. Your care team can help you understand and adapt to these changes.

## DISORIENTATION AND CONFUSION

It is not unusual for the dying person to become confused about times, where they are, and even the identity of people around them as their disease progresses.

## APPROACHING DEATH

A person prepares to die emotionally and spiritually as well as physically. Death occurs when the body completes the natural process of shutting down. Remember that no two people go through this process in the same way and in the same time.

In the last weeks and months...	In the last days and weeks...	In the last hours and days...
<ul style="list-style-type: none"> <li>▪ Withdrawal from family and friends</li> <li>▪ Lack of interest in activities</li> <li>▪ Inward focus</li> <li>▪ Decreased appetite</li> <li>▪ Increased sleep</li> <li>▪ Weakness and fatigue</li> </ul>	<ul style="list-style-type: none"> <li>▪ Confusion and disorientation</li> <li>▪ Changes in blood pressure, pulse, and body temperature</li> <li>▪ Increased sweating</li> <li>▪ Changes in skin color</li> <li>▪ Breathing changes</li> <li>▪ Near death awareness</li> </ul>	<ul style="list-style-type: none"> <li>▪ Sometimes a last surge of energy or activity</li> <li>▪ Continuation of earlier signs</li> <li>▪ Restlessness</li> <li>▪ Irregular breathing and noisy breathing</li> <li>▪ Purplish discoloration (mottling) of hands and feet and underside</li> <li>▪ Unresponsive</li> </ul>

You may hear your care team say that your loved one is “actively dying.” This means that they have begun to show physical signs that death is imminent. “Active dying” can take several hours or several days, so it is impossible to predict exactly when death will occur.

There are some common signs of approaching death, but because individuals vary so greatly, not every person experiences all of them. You may or may not see these signs.

## Physical signs of approaching death

- **Skin temperature and color:** As circulation slows, the skin, particularly in the arms and legs, may feel cool and may deepen in color or look mottled. Other areas of the body may appear bluish or pale. Keep your loved one warm with blankets, but avoid electric blankets.
- **Restlessness and agitation:** Prior to death, some people become restless, confused and even agitated. This is certainly not true for everyone, but it does happen. People may move around in bed and try to get up. They pull at clothes and bed linens, call out and seem unable to rest calmly.

Your care team will work with you to figure out what may be causing this distress and work to restore peace and comfort. Getting your care team involved is important. Please call your care team right away.

Spend time with your loved one during alert periods. Your loved one may be comforted by the presence of a familiar person at night, when restlessness and anxiety are magnified.

- **Breathing:** There are a few different ways that breathing changes during the dying process. You may notice:
  - Noisy or rattling breath
  - Shallow, irregular breathing with periods of no breathing (apnea) for up to 30 seconds or longer.
  - Panting-type breaths.

Although disturbing to hear, these changes do not mean that the person is suffocating or drowning. By the time this changes happens, the dying person is usually not fully conscious and does not seem to be aware of or distressed by this symptom.

A decrease in fluid intake and an inability to cough up saliva may result in an increase of mucus at the back of the throat, producing a gurgling sound from the chest (sometimes called the “death rattle.”)

Raising the head of the bed or using pillows to prop your loved one’s head and chest on an angle can relieve some of the breathing difficulties. Be sure to tell your Hospice nurse if the patient is having trouble breathing. Medication can sometimes help.

The pattern of breathing will shift and change. You may notice irregular breaths with periods of no breathing. These pauses (apnea) may last for longer periods of time. Breathing may become heavy and deeper, or very shallow and quick. Silent, gasping movements of the mouth without taking in any air may happen in the last minutes of life. Often the last breaths are deep and sighing.

It can be helpful to:

- Elevate the head of the bed
- Turn the person from side to side
- Avoid suctioning, which has little effect and will often cause more congestion and discomfort
- Using a soft damp cloth wrapped around your finger, gently wipe the mouth of any secretions that accumulate
- Ask your care team for their suggestions. Medication may help dry up the moisture that causes noisy breathing but can leave other areas like the mouth, nose and eyes dry as well.
- **Elimination:** Loss of urine and bowel control is common when death is imminent. The urine usually becomes darker and decreases in amount. Other signs include a decreased swallowing reflex, skin breakdown and fever.

Use waterproof pads under the patient to lessen the need for linen changes.

## THE FINAL HOURS

### Vision-like experiences

Your loved one may speak to, or claim to have spoken to, persons who have died. The dying person may see places that are not presently accessible or visible to you. This does not necessarily mean that your loved one is having a hallucination or drug reaction. As the patient begins to detach from this life and prepares to die, these visions may reduce fear. These events are normal and common. If your loved one appears frightened, provide calm reassurance that this experience is normal.

This is a precious time to share with your loved one. Listen. Do not contradict, explain away, correct or argue. You may ask yourself:

- Does the rambling speech have a message?
- Does the vision bring a smile or look of wonder?
- Does the body seem to relax?
- Does the person speak of beauty and light?

Offer expressions of acceptance, sharing and comfort:

- Is it beautiful, peaceful?
- Are you seeing someone from your past?
- Allow the person to share this experience with you without judgment or correction.

### Giving permission

It can be very difficult to give permission for your loved one to let go, because you want to keep your loved one with you. A dying person will often try to hold on, even in prolonged discomfort, in order to be sure that those who will be left behind will be all right. Assuring the person that you'll be all right is one of the best gifts you can give your loved one at this time.

## Saying goodbye

When the person is ready to die and you are able to let go, then it is time to say goodbye. Saying goodbye is your final gift of love to your loved one. Saying goodbye achieves closure and makes the final release possible. It may be helpful to lie beside the person and give a hug, or take a hand and say everything you need to say. It may be as simple as “I love you.” You may recount favorite memories, places and activities you have shared. Your farewell also may include saying “I’m sorry” for actions you regret or “Thank you” for things your loved one has done.

Tears are a normal and natural part of saying goodbye. You don’t have to hide your tears or apologize for crying. Tears express your love and help you to let go.

## WHEN DEATH OCCURS

Even if you have known that someone may die very soon, you may feel unprepared for the actual moment of death. It is difficult to grasp that this time has actually come. Some people take their last breaths holding someone’s hand in the company of loved ones. Others quietly slip away. As each person lives differently, each makes this transition in his or her own way. When you think death has occurred, you will see certain signs:

- Placing a hand on the chest, you will no longer feel a heartbeat.
- The chest will not rise and fall for at least five minutes.
- The jaw is relaxed and the mouth opens.
- Eyelids may be half-closed.
- Hands, legs or feet will feel cool or cold.



Contact Arbor Hospice when you believe your loved one has stopped breathing. When you call, a staff member will answer the phone and provide guidance. Arbor Hospice will then contact you to support you and your family and inform you of their arrival time.

In some cases, the Medical Examiner may need to be contacted by the Arbor Hospice RNCM. Your care team will explain the requirements if this should apply.

Arbor Hospice will contact the durable medical equipment company to request pick-up of any equipment. The durable medical equipment company will contact you directly to schedule a convenient time for equipment pick-up. A staff member will come to your home and assist you in notifying the local authorities and then contacting the funeral home.

#### **When death occurs in a hospital or nursing home**

When the death happens in a hospital or nursing home, the facility's protocol will be followed for pronouncing the death and contacting the physician. Arbor Hospice is also notified by the facility staff so that a hospice team member can be present to offer support and assistance. You and your hospice care team can be as involved as you choose to be on the care that takes place at that time. Think about whether or not you want to see your loved one before his or her body is removed from the room. Talk to your care team so they can work together with the care facility to make a plan that honors your wishes.

**DO NOT CALL EMS (911)**

If you call 911, an emergency crew will respond and possibly start resuscitation efforts or take your loved one to the hospital. Call Arbor Hospice and they will guide you through the next steps. It is helpful to minimize telephone calls to other relatives and friends until the hospice staff arrives.

**Part 6:****What will happen after your loved one's death?****GRIEVING**

The Arbor Hospice grief support staff continues to offer emotional support to family and friends after the death by providing a variety of services.

**What grief support is offered to grieving family and friends?**

- Supportive counseling is available and gives individuals and families an opportunity to share the grief and emotions they are experiencing related to the death of their loved one.
- Grief seminars and support groups are offered to those learning how to live with the loss of someone they love. Groups can provide a safe and supportive environment for participants to express their thoughts and feelings while increasing their awareness of the grief experience. Many participants say it is most helpful to be with others who can understand what they're going through and that what they are feeling is normal.
- Children and youth services tailored to the specific needs of children and young people are available in the communities we serve. Professional staff use proven educational and supportive techniques to help children and adolescents cope with their loss. Both individual and family support are offered.
- Mailings are sent to Arbor Hospice families at regular intervals during the year following the death of a loved one. This is another way of letting you know that you are not forgotten.

## What is grief?

- a normal and natural reaction to a significant loss
- a personal and individual experience
- a process that takes place over time
- random and unpredictable, it does not occur in any set order

## What is most helpful as we grieve?

- having information on expected, normal behaviors and on available resources
- giving ourselves permission to grieve, to express feelings
- finding good listeners, those who understand us and our pain
- accepting the support of others (this may make our grief a little easier to bear)

## The Journey Through Grief

When we lose a loved one through death, the grief can be so painful and overwhelming that it may frighten us. Some people worry whether they are mourning the “right way” and wonder if the feelings they have are normal or natural. It is helpful to have some understanding of the different dimensions of the grieving process.

Each person mourns in their own unique manner. Not recognizing this can lead to misunderstanding among family members, friends and associates. A person may experience each reaction described, or only a few. Likewise, the mourning process does not necessarily occur in any particular order. Much depends on our unique cultural and religious background, personality, support system and relationship to the deceased, among other factors.

**Part 7:**  
**Emergency Response Plans**

**PATIENT/FAMILY EMERGENCY  
RESPONSE PLAN**

IF A LOCAL EMERGENCY SITUATION OCCURS (WEATHER/POWER OUTAGE), ARBOR HOSPICE WILL MAKE AN ATTEMPT TO CONTACT YOU.

In the event of an emergency, we will contact patients based on their individual circumstances (i.e.: safety, progression of pain and symptoms, etc.)

If you have not been contacted and require basic information, or if you have an emergency situation and need to speak to someone: **Call 888-992-2273**. It is answered 24 hours a day, 7 days a week.

**Weather / Power Situations:**

1. Stay tuned to your local radio station for general safety instructions and news updates.
2. If the patient is oxygen dependent:
  - a. Inventory the oxygen to estimate the supply on hand
  - b. Attempt to locate an alternate source of power
  - c. Call Arbor Hospice to report status
3. Make arrangements to stay with a relative or friend if your power is out. Inform Arbor Hospice of the new phone number and address at which you are receiving care.
4. Contact your local community government office to find out the location and phone number of an emergency shelter in your area:

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5. If death occurs and you are unable to reach Arbor Hospice, contact your local police department:

Phone \_\_\_\_\_

Address \_\_\_\_\_

When the police officer arrives, give him/her your Arbor Hospice folder.

Contact the funeral home:

Name \_\_\_\_\_

Phone \_\_\_\_\_

Address \_\_\_\_\_

**NOTE:** If the phones are out of order, this may require a family member or friend going to the police department or funeral home to notify them of the death.

6. Prior to an actual emergency, consider stocking bottled water and canned shelf-stable food supply.
7. Important documents should be maintained in a water- and fire-safe vessel.
8. If you have pets, assemble an animal emergency supply kit. Suggestions for contents can be found at [http://www.ready.gov/sites/default/files/documents/files/pets\\_brochure.pdf](http://www.ready.gov/sites/default/files/documents/files/pets_brochure.pdf)

### **TORNADO SAFETY**

- If possible, move to underground shelter in case of a tornado.
- Close windows and draw drapes to prevent injury from flying debris.
- Turn on a portable radio.
- Seek shelter on inside walls away from doors and windows or go into a large closet, under beds or heavy tables, or in a dry bathtub (providing there are no glass shower doors).

Since 1984, Arbor Hospice has been committed to providing quality compassionate care for those experiencing life-limiting illnesses. Arbor Hospice, a not-for-profit organization, is integrated into the community with the help of its experienced staff and caring volunteers through its certified hospice services, in-patient hospice facility, grief support services and community education programs. Arbor Hospice serves communities in Jackson, Lenawee, Livingston, Monroe and Washtenaw counties.

As a member of the NorthStar Care Community, we collaborate with other not-for-profit providers, sharing a goal to continually provide unsurpassed care, guidance and quality of life for patients facing serious illness, which includes practicing the highest standards of hospice and palliative care. Collectively, we touch the lives of more than 6,000 patients and families annually.



888-992-CARE | [www.arborhospice.org](http://www.arborhospice.org)

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WE HONOR VETERANS



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A member of the  Care Community