Dear Bon Secours Hospice Patient and Family,

Thank you for choosing Bon Secours Hospice. Our health care system started over 100 years ago with the Sisters of Bon Secours providing care in the home setting. Our agency has deep roots in the community and a commitment to serving patients and families in their home.

We have a wonderful, caring interdisciplinary team of professionals who meet weekly on Thursday mornings at 10 a.m. to discuss patient and family plans of care. We welcome your attendance and participation as we seek to provide excellent palliative care and support. Our interdisciplinary team is comprised of a medical director, nurses, social workers, chaplain, volunteers and bereavement support. Our goal is to provide excellent service.

Please contact our office support staff if you would like more information about the interdisciplinary team meetings. Our office support staff is also happy to assist with any questions or requests you may have and can be reached by calling (757) 391-6017.

You will receive excellent quality patient care and caregiver support from the Bon Secours Hospice team. Please do not hesitate to contact me with any comments or compliments you may have by calling (757) 391-6028.

Thank you for allowing Bon Secours Hospice to serve you.

Sincerely,

Sharon K. Riddick, RN

Sharon Riddick, RN
Administrative Director

BON SECOURS HEALTH SYSTEM, INC.

PUBLIC NOTICE

The Joint Commission
conducts accreditation surveys of Bon Secours Health System's
health care facilities on an unannounced basis.

The purpose of a survey is to evaluate the organization's compliance
with nationally established Joint Commission standards.
The survey results are used to determine whether,
and the conditions under which, accreditation
should be awarded to the organization.

Joint Commission standards deal with organization quality,
safety-of-care issues, and the safety of the environment
in which care is provided. Anyone believing that he or she has pertinent
and valid information about such matters is encouraged to
contact the organization's management.
If the concerns in question cannot be resolved at this level,
please contact a Joint Commission field representative.
Information presented will be carefully evaluated for relevance
to the accreditation process.
Information about such matters must be made in writing and
must also indicate the nature of the concerns.

Such requests should be addressed to:
Division of Accreditation Operations
Office of Quality Monitoring
The Joint Commission
One Renaissance Boulevard
Oakbrook Terrace, Illinois 60181
or
Telephoned in to 1-800-994-6610
or
Faxed to 630-792-5636
or
E-mailed to complaint@jointcommission.org

This notice is posted in accordance with The Joint Commission's requirements.

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NOTES

MISSION

Our Mission is to provide compassionate, quality health care services to those in need, including the poor and the dying, for the purpose of alleviating human suffering and bringing people to wholeness in the midst of pain and loss.

Hospice is a Team

All team members work together with their special training in hospice care to meet the needs of the patient, the caregiver and the family.

Medical director: The medical director is a licensed, practicing physician in the state of Virginia and is the hospice team member with ultimate responsibility for medical aspects of hospice patient care and program policy. The medical director serves as part of the team and may also serve as the attending physician for patients in the program.

Physician: The primary physician, who is a member of the hospice team, informs the patient and family of the life-limiting illness, makes a recommendation for hospice services, and orders medications and treatments. Ongoing communication between the physician and the hospice team members occurs even when the patient can no longer visit the physician in the office.

Nurse: A nurse visits the home on an intermittent and emergency basis to evaluate physical symptoms and limitations and to identify needs for equipment and supplies. The nurse frequently discusses the control of symptoms and the condition of the patient with the physician and makes changes in medications and the plan of care as needed. The number of visits may increase as the patient's condition changes. Because these changes may occur at any time, an on-call nurse is available **24 hours a day for emergencies.**

Home health aide: A home health aide may assist the patient with bathing and personal care on a regular basis.

Social worker: A medical social worker assists families with emotional and social needs. The social worker also assists with financial needs and with advance directives.

Consultant pharmacist: The consultant pharmacist manages the pharmaceutical care of hospice patients and provides drug information and education to the hospice staff, patients, and their families.

Bereavement coordinator: The bereavement coordinator works with families by offering support through the grief experience. They maintain contact with caregivers and families for 13 months after the death of a loved one.

Chaplain: Chaplain services are available for spiritual support and guidance. Your personal minister or pastor may visit, or you may choose not to receive pastoral visits.

Volunteers: Based on availability, volunteers visit on a regular basis or for one-time needs. They assist with providing companionship, meal preparation, running errands, light housekeeping, limited respite and a wide variety of other tasks. Many have experienced a loved one's death and know what you are going through.

AFTER HOURS — WHEN YOU NEED HELP

During business hours, if you need assistance, please call and ask for your primary nurse. After business hours, please call and ask for the hospice nurse on-call. An on-call nurse is available after 4 p.m. until 8 a.m. on weekdays and 24 hours on Saturdays, Sundays and holidays to assist with emergencies.

Call (757) 391-6017 and give the following information:

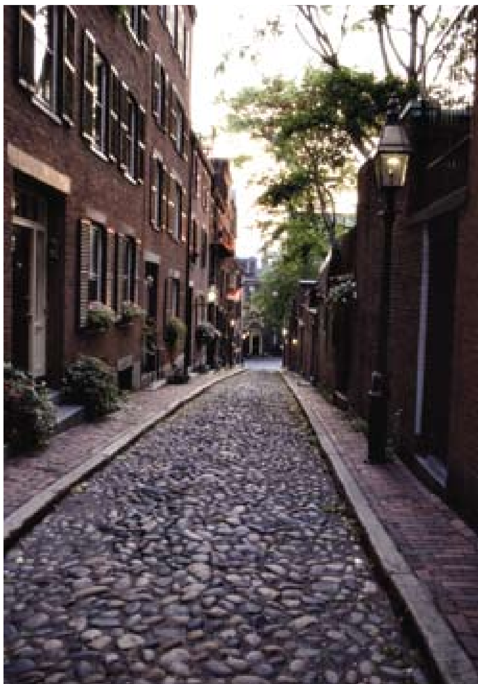
1. The patient's name
2. Your name
3. The phone number
4. The problem

A nurse will return your call within approximately 15 minutes. **Please keep your phone line clear for the return call. Always call back if your call has not been returned within 15 minutes. After talking with you on the phone, the nurse will visit your home if needed.**

Emergencies Include

- Pain unrelieved with medication
- Vomiting unrelieved with medication
- Unexpected changes in condition, such as fever, confusion, shortness of breath
- Falls
- Death of the patient
- If you are not sure, CALL and let the nurse hear your concerns

For medication refills and supplies, please call during office hours when your primary physician may be contacted.



After Dark — When the Nurse Visits

Please turn your outside lights on near the door and house number.

If you are able to, please clear a parking space close to the residence where the hospice nurse can park.

Please be aware of the need for safety. If the nurse or staff member feels they cannot enter the home safely, they will contact you by phone and use other methods to help you with the emergency.

GENERAL INFORMATION

Emergency room visits can be long and uncomfortable. **CALL HOSPICE FIRST!**

- Always tell the laboratory, X-ray department and the physician's office that you are a hospice patient. **Pre-authorization by hospice is required for these services if a patient has elected the hospice Medicare or Medicaid benefit. Failure to get pre-authorization from hospice may result in the patient being billed for some services.**
- Before purchasing supplies needed for the patient's care, ask the hospice nurse if these can be provided by hospice. Hospice supplies 2 packs of diapers and Chux per week, 2 tubes of Cavalon Cream per month as well as 2 boxes of gloves per month.
- Supplies are ordered and will be delivered to the house by FedEx. This process takes two days.
- **Do not wait for a crisis. If you have questions or feel that you are not able to control symptoms, don't wait — call!**
- If you have a concern or complaint, we want to know. Please call our hospice director or team leader: Monday – Friday at (757) 391-6017.
- **Hospice does not pay for 911 emergency medical services.** Please call hospice before calling 911. Medicare or Medicaid may not pay for 911 emergency services once a patient has elected the hospice Medicare or Medicaid benefit.
- Bon Secours Hospice accepts patients whether or not the patient is able to pay for services.
- Donations from individuals' memorial gifts, bequests through wills, and organizational contributions allow us to serve everyone in need of hospice services.

CAREGIVER NOTES

You have accepted a new role in your life as a caregiver of a person with a life-limiting illness. You are giving a gift of yourself. Remember, this does not mean you give up yourself, or that you have to carry out this new role alone. Friends, relatives and the hospice team want to help. Without assistance, the tasks may become overwhelming, draining you physically and emotionally.

Each person's experience is different as they face the death of a loved one. **There is no right or wrong way.** No other event in life will bring as many emotions to the surface as watching someone you love slowly journey from your world to a world you are not ready to enter. During this time it is important that you take care of yourself, too.

- **Take time for yourself.** Ask friends to sit with the patient so you can get out of the house on a regular basis.
- **Exercise** by walking or stretching your arms and legs for 20-30 minutes several times a week. Stress will be released and your energy level will increase.
- **Eat a balanced diet.** Review your diet over the last 3 days. This will give you an idea if you are not eating right.
- **Do not deny** your pleasures but try not to overuse caffeine, tobacco or alcohol. They will further drain your energy.
- **Rest and sleep are important.** Some things around the home may need to be left undone when a nap is needed.
- **Ask friends** not to call during certain times of rest. Ask your hospice team for help with notices to limit visitors.
- **Report** the patient's sleeplessness to the primary nurse.
- **Make a Sunshine List** with little things that would brighten the days for you and the patient. Keep it handy to share with others when they ask, "How can I help?" or "What do you need?" Loved ones want to feel needed and often don't know how to help. Instead of answering the question with "I don't know," or "Nothing," share the list and they can choose. Sunshine list items may include:
  - **Regular household duties** like dusting, changing beds, preparing a meal or trips to the grocery store for small items.
  - **Gifts** such as lotion, baby wipes, note cards, a flower.
  - **Help with the patient,** such as massaging feet or back, sitting and talking with the patient, reading to the patient, sharing old photographs with the patient, etc.

Sunshine List

SAFETY IN THE HOME

Home accidents are a major cause of injury and death, especially for those over 60. As people grow older, they may be less agile and their bones tend to break more easily. A simple fall can result in disabling injury. All patients need to take special precautions to ensure a safe living environment. Most accidents in the home can be prevented by the elimination of hazards.

Use the "Check for Safety" booklet to determine the safety level of your home.
Check each statement that applies to your home or to your habits in your home. Then review the unchecked boxes to determine what else you can do to make your home a safer place to live.

General Safety

- Emergency phone numbers are posted by each telephone.
- Outside doors are kept locked at all times. Do not open the door to an unfamiliar face. Ask for identification and call someone to verify who they say they are.
- Door-to-door salesmen are not let into your home. They are asked to come back when a friend or family member will be with you.
- Valuables that may be easily stolen are kept out of sight.
- Telephone and television solicitations are not accepted. If it sounds too good to be true, it probably is.
- Household maintenance (painting, roofing, etc.) is scheduled with a reputable company. Have a friend or family member assist you.

Electrical Safety

- Electrical appliances and cords are clean and in good condition and not exposed to liquids.
- Electrical equipment bears the Underwriters Labs (UL) label.
- An adequate number of outlets are located in each room where needed. There are no "octopus" outlets with several plugs being used.
- Electrical outlets are grounded.
- Lighting throughout the house is adequate.
- Burned-out lights are replaced.
- Repair or replace frayed, broken or brittle cords.
- Keep cords from under rugs, through doorways or across walkways.
- Keep cords away from heat sources and appliances and away from oil or water.
- Use extension cords only temporarily.

Preventing Falls

- Use night lights in bathrooms, halls and kitchen.
- Light switches are located at the top and bottom of stairways and at both ends of long halls.
- A flashlight with good batteries or a lamp is within easy reach of your bed.
- Throw rugs are removed or have a nonskid backing and are not placed in traffic areas.

- Clear all clutter from the house, especially from pathways.
- Electrical and telephone cords are placed along walls — not under rugs — and away from traffic areas and do not cross pathways.
- There are no step stools without high handrails.
- Clearance in the stairway provides adequate head room.
- Stairways and halls are well lit.
- Use handrails on stairs. To avoid a fall, never leave objects on steps. Make sure handrails are securely fastened.
- Steps are in good condition and free of objects.
- Steps have non-skid strips or carpeting is securely fastened and is free from holes and fraying.
- Be aware of coffee tables, hassocks and stools to keep from tripping over them.
- Spills are cleaned up immediately.
- You are aware of any medications being taken which may cause dizziness or unsteadiness.
- Alcoholic beverages are limited to no more than two per day.
- When seated or lying down, stand up slowly.
- A cane can be used for extra stability.
- Outside walks are kept clear of snow and ice in the winter.
- Outside steps and entrances are well lit.

Kitchen Safety

- Stove and sink areas are well lit.
- Curtains are kept away from the stove and other open flame areas.
- Exhaust fans are turned on when cooking.
- Kitchen exhaust system discharges directly outside.
- Adequate counter space is available to keep from lifting or carrying.
- Counter space is kept clean and uncluttered.
- Pan handles are turned away from burners and the edge of the stove.
- Hot pan holders are kept near the stove.
- Microwave oven is operated only when food is in it.
- Heavy items are not stored above your easy reach.
- Cooking on high heat with oils and fat is avoided.
- Clothing with loose sleeves is not worn when cooking.
- Refrigeration and proper storage are used to avoid food poisoning.
- Perishable foods are kept refrigerated and periodically checked for freshness.
- Kitchen appliances are turned off when they are not being used.

Bathroom Safety

- Bath tub or shower has a non-skid mat or strips in the standing area.
- Bath tub or shower doors are glazed with safety glass or plastic.
- Grab bars are installed on the walls by the tub or toilet. Handrails may be needed to enter or exit tub or shower.
- Towel bars and soap dish in the shower are made of durable materials and are firmly installed and are not used as grab bars.
- Keep electrical equipment away from water. If medical equipment gets wet, call the equipment company and ask for it to be checked or replaced.
- The water heater thermostat is set below 120° F to prevent accidental scalding.
- Night lights are used to brighten the way to the bathroom at night.
- Use a tub or shower chair if it is difficult getting in and out of tub.

Outside Areas

- Steps and walkways are in good condition and free of objects.
- Porches, balconies, terraces and other elevations or depressions are protected by railings or otherwise protected.
- The garage is adequately ventilated.
- Large trees are healthy and have no dead limbs.

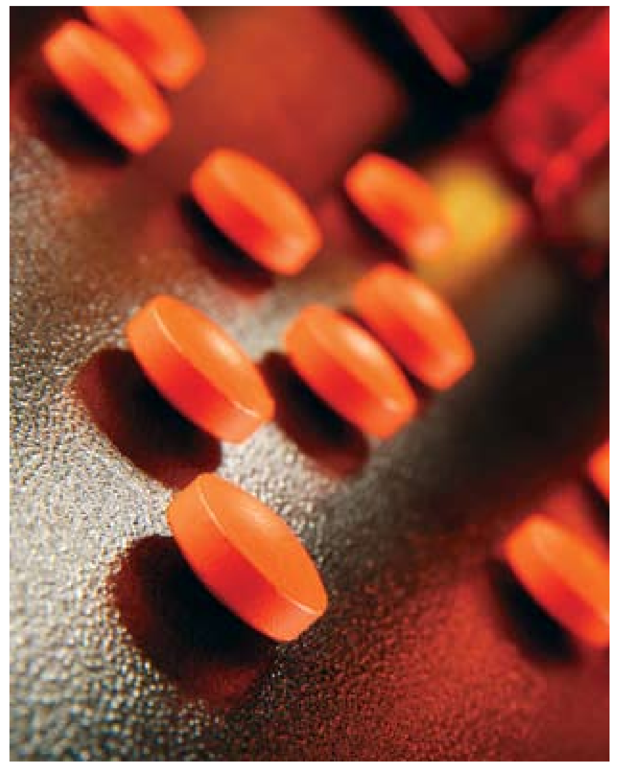
Hazardous Items and Poisons

- Care is used in storage of hazardous items. They are stored only in their original containers.
- You know how to contact your poison control team.
- Products that contain chlorine or bleach are not mixed with other chemicals.
- The risk of insecticides is understood. They are only bought for immediate need, and excess is stored or disposed of properly.
- Hazardous items, cleaners and chemicals are kept out of reach of children and confused or impaired adults.
- Household trash is disposed of in a covered waste receptacle outside the home.

Medication Safety

- Never take medications that are prescribed for someone else.
- All of your medications are written down and the list shown to your doctor or pharmacist to keep from combining drugs inappropriately. If there are any changes, they are added to the list immediately.
- Know the name of each of your medicines; why you are taking it; how to take it and its potential side effects.
- Medication side effects are reported to your health care provider.
- Medications are taken exactly as instructed.
- Alcohol is NOT used when you are taking medicine.

- Medicines are not stopped or changed without your doctor's approval, even if you are feeling better.
- The chart or container system (egg carton or med-planner) is used to help you remember what kind, how much, and when to take medicine.
- Your medicine is taken with a light on so you can read the label.
- Medicine labels are read carefully and medicines are kept in their original containers.
- Medications are stored safely in a cool, dry place according to instructions on the label of the medication.
- If you miss a dose, you do not double the next dose later.
- Old medications are disposed of as directed.
- Medicines are kept away from children.



Medical Equipment/Oxygen

- Manufacturer's instructions for specialized medical equipment should be kept with or near the equipment and are followed for providing a proper environment.
- Routine and preventive maintenance is performed according to the manufacturer's instructions.
- Phone numbers are available in the home to obtain service in case of equipment problems or equipment failure.
- Backup equipment is available if indicated and you are proficient in its use in the event of power outage.
- Adequate electrical power is provided for medical equipment such as oxygen concentrators and other equipment.
- Equipment batteries are checked regularly by a qualified service person.
- All oxygen equipment is kept away from open flame. There is no smoking around oxygen.
- Oxygen is not allowed to freeze or overheat.
- If you have electrically powered equipment such as oxygen or ventilator, you should register with your local utility company.

Fire Safety Precautions

- All family members and caregivers are familiar with emergency 911 procedures.
- The fire department is notified if a disabled person is in the home.
- Do not smoke in bed or when oxygen equipment is being used. Provide deep ashtrays for smokers. Wet all cigarette butts before throwing them into the trash.
- Keep matches and lighters out of the reach of children.
- The heating system is checked and cleaned regularly by someone qualified to do maintenance. Space heaters, if used, are maintained and used according to the manufacturer's specifications.
- Unplug, repair or throw away an appliance that smokes or smells like it is burning.

- Turn space heaters off when leaving the home and keep them at least 36 inches away from all other objects.
- Have two escape routes planned, ensuring that first floor windows open easily.
- If you live in an apartment building, you know the exit stairs location.
- Hallways are kept clean and elevators are not used in a fire emergency.
- A fire drill/safety plan is prepared.
- An escape route is practiced from each room in your home.
- Fire extinguishers are checked frequently for stability.
- Smoke detectors are in place in hallways and near sleeping areas. Have at least one on each floor and check them regularly.
- Smoke alarm batteries are checked and installed when you change your clocks for daylight savings time in the spring and fall.
- If your fire escape is cut off, remain calm, close the door and seal cracks to hold back smoke. Signal for help at the window.
- Remember, life safety is first, but if the fire is contained and small, you may be able to use your fire extinguisher until the fire department arrives.

Evacuation of a bed-bound patient:

- One or two persons can get the patient to safety by placing the patient on a sturdy blanket and pulling/dragging the patient out of the home.

Restraint Education Sheet

Bon Secours Home Care wishes to provide you, the caregiver, with information on safe care in the home. Sometimes restraints may be needed to provide this care. A restraint limits freedom of movement and prevents injury. Restraints may be either a device or medication. Please review the following list of safety precautions and ask your home care nurse or therapist if you have any questions.

Alternatives to using restraints:

- Try to avoid restraining whenever possible.
- Increase supervision — don't leave the patient alone.
- Make the home safe — clear pathways, remove scatter rugs, lower water temperature.
- Confine to a small, safety-proofed area — no stoves, sharp corners, stairs and sharp utensils.
- Discourage smoking.

Application of restraints:

- Pad affected limb (if arm or leg restraint)
- Fasten end of device to frame of chair or bed, never to side rails or moveable objects.
- Slightly bend arm or leg before securing limb. Leave as much slack as possible to allow for movement.
- When applying a waist or jacket restraint, leave enough room to be able to put a hand underneath the belt.

Chemical restraints:

- Any drugs that are used to control behavioral symptoms. Behavioral symptoms are actions used when a patient is unable to communicate verbally due to a medical condition, which expresses distress.
- Some examples of behavioral symptoms include: anger, agitation, screaming, continuous wandering, pacing, repetitive actions or paranoia.

Special needs while using a restraint:

- Avoid using restraints more than necessary.
- Explain to the patient why restraints are necessary and offer reassurance that their needs will be met.
- Avoid uncomfortable positions.
- Provide privacy — keep covered with blanket for toileting.
- Treat with dignity — talk to patient, read to patient.
- Place clock and/or calendar within eyesight of patient.
- Place articles such as water and telephone within reach.
- Check patient often.
- Make sure needs are met — water, food, toileting, warmth.
- Check continued need for restraint.
- Never restrain feet.
- If medication is ordered, your pharmacist or nurse will provide information on safe use.

MEDICAL EQUIPMENT

Bedside Commode

Instructions for use:

- The bedside commode should be adjusted to a height that is comfortable for the patient when sitting.
- To adjust the bedside commode:
  — Locate the push button on each leg and depress the push button.
  — To adjust the commode higher, pull the extension down. Once you have reached the desired height, align the push button with the hole and the push button will "pop" into place and lock.
  — To adjust the commode lower, push the extension up into the outer tube. Once you have reached the desired height, align the push button with the hole and the push button will "pop" into position and lock in place.
  — To ensure that the legs are locked into position, the push button will protrude just a little from the hole. You will be able to see the push button.
- Raise the toilet seat and remove the pail cover before using.
- If using the bedside commode over the toilet, replace the bucket with the open sleeve that came with the commode.

Cleaning of bedside commodes:

- Clean the toilet seat and frame with any household bathroom cleaner.
- Clean the pail and cover with any toilet bowl cleaner and water.
- Deodorizer may be used if needed.

Standard Wheelchair Equipment

Instructions for use:

- To unfold, push armrests away from each another until wheelchair seat is extended.
- To fold, fold armrests or lift up on the center of the seat. The frame will fold when this is done.
- When entering or exiting wheelchair, **ALWAYS ENGAGE THE WHEEL LOCKS!** The wheel locks are engaged by pressing down on the levers located on each side of the wheelchair frame and just in front of the wheel rims. Push the lever until it locks into place.

Removable arms (if applicable):

- To remove arms, push button on armrest at the level of the seat and lift up on the armrest.
- To replace arms, align armrest with slots in wheelchair frame, insert and push down on the armrest. The armrest will lock into place.

Swing away foot and leg rest (if applicable):

- To swing foot of leg rest away for entering or exiting the chair, push lever on side of foot or leg rest where it attaches to the wheelchair frame and "swing" the foot or leg rest away.
- To lock foot or leg rest back into position: swing foot or leg back towards the front of the chair. The leg rest will lock into position.
- To remove foot or leg rest, follow first instruction.
  — When foot or leg rest is positioned at the side, lift up to remove.
- To replace foot or leg rest: align pins on wheelchair frame with the holes in the foot or leg rest. Engage and swing the foot or leg rest back towards the front of the chair. The foot or leg rest will lock into position.

Cleaning instructions:

- Clean upholstery, arm pads, and foot or leg rest with warm soapy water.
- Keep wheels and axles free from dirt, dust and hair.

OXYGEN SAFETY

Oxygen is very safe to use when you create the proper conditions. Tips for use include:

- Keep oxygen equipment and oxygen tubing at least 10 feet away from any open flame.
- Keep equipment and tubing away from all flammable materials such as oil, grease, Vaseline and aerosol sprays.
- Do not permit smoking in the same room as your oxygen equipment.
- Do not use an extension cord with the concentrator.
- Keep the concentrator at least one foot away from drapes, bedspreads, walls or any other items that might block the inlet areas.

Oxygen Concentrator Instructions For Use

- Plug the unit into a grounded electrical outlet.
- Attach your tubing and nose piece to the concentrator.
  — Locate the oxygen outlet port in the front of the unit.
  — Attach one end of the tubing to the port.
  — Attach the other end of the tubing to the nose piece.
- Turn on the concentrator by pushing the lighted on/off switch to the "ON" position.
- To set the liter flow, turn the flow meter knob. Turning the knob clockwise will decrease the flow, while turning counterclockwise will increase the flow. The knob should be turned until the ball in the flow meter is centered on the line next to the number of your prescribed flow rate.

Note: Your liter flow has been set by the technician upon initial delivery. The liter flow should not be changed unless authorized by hospice.

Cleaning the Unit:

- The outside of the unit may be wiped clean with a damp cloth.
- Keep the unit as dust free as possible.
- Remove and clean the filter as explained by the equipment company.

Using Your Back-Up System:

- If you experience a power outage, or the concentrator stops working, use the back-up tank.
- Attach your tubing and nosepiece to the back-up tank regulator outlet.
- Turn the back-up tank knob counterclockwise to turn the tank on. The back-up tank knob is located on top of the tank.
- Locate the flow meter knob on the back of the regulator. This is a small black knob.
- Turn the flow meter knob to adjust your liter flow, if it is not adjusted properly.

Ordering Oxygen

If you use portable oxygen and need to order an additional tank:

- Call your hospice nurse at least 24 hours in advance to place an order.
- Check your supply of portable oxygen before the weekend to ensure you have enough.
- If you are having trouble with your equipment, call Bon Secours Hospice.

Oxygen Usage and Handling Guidelines For Patients and Caregivers

Oxygen by itself is not flammable or explosive; however, it does violently accelerate the combustion of any flammable or explosive materials. A normally non-flammable material may become flammable in an oxygen-enriched environment. Extreme caution should be displayed when storing or using oxygen in either its gaseous or liquid form. Please read the following guidelines carefully:

Oxygen usage basics:

- In the case of fire, close all open oxygen vessels and evacuate the area.
- Compressed oxygen should not be used to power pneumatic tools.
- Avoid using oxygen in a tightly confined area.
- Never carry or store an oxygen vessel in a tightly closed space like a car trunk or closet.
- Do not lay the oxygen cannula or mask on any flammable material with the oxygen flowing when not in use. For example, laying the cannula with oxygen flowing on the bed covers will result in the saturation of the cover with oxygen. This could result in dangerous fire if the bed covers were to become ignited.
- Avoid using oxygen in an area with open flames.
- Do not allow oxygen to touch Vaseline, petroleum jelly, oil or grease. Fire may result.
- Keep tanks away from any source of heat or electrical cords and appliances.
- Do not store flammable gasses or liquids in the same room as oxygen.
- Do not attempt to dispose of unused oxygen. All vessels must be returned to the equipment rental company.
- Do not attempt to repair or alter any oxygen vessel. Call hospice or the supplier.

<u>Do NOT</u> use oxygen with any petroleum products such as Vaseline, oil or grease. Fire will result.

Liquid oxygen handling:

- Do not allow liquid to touch the skin. Severe burns will result. Liquid oxygen is extremely cold.
- Do not fill the portable tank over asphalt. An explosion may occur.
- Fill portable tanks only in well-ventilated areas and away from open flames.
- Always keep liquid vessels in an upright position.

Oxygen tank handling:

- Never permit oxygen to enter the regulator suddenly. **Always open tank first and regulator second.**
- Do not store oxygen tanks in a closely confined area such as a closet.
- When possible, store oxygen tanks in their specifically designed stands or carts.
- **When stands or carts are not available, store tanks by lying them down on the floor in the horizontal position. Failure to do so could result in serious injury.**
- Store empty and full tanks separately.

Oxygen Concentrator Troubleshooting Guidelines

If you experience difficulty with your oxygen concentrator, please follow the guidelines listed below. If you are unable to resolve the problem, call **Bon Secours Hospice at (757) 391-6017.**

No oxygen flow:

If you do not feel that oxygen is coming through the nosepiece, place the end of your nosepiece in a small glass of water and look for a flow of bubbles. If you can see the bubbles, there is flow coming through your nosepiece. If you do not see any bubbles coming from your noisepiece, check to see that:

- Your oxygen concentrator is plugged in and turned on.
- Your flow meter is set to your prescribed flow.
- Your nosepiece is attached to your tubing.
- Your oxygen tubing is attached to your oxygen concentrator.

Water in the oxygen tubing:

If you are using a humidifier on your oxygen concentrator, you will occasionally experience an accumulation of moisture in your oxygen tubing. This can be caused by overfilling your humidifier bottle, or your tubing lying on a cold floor. When this occurs:

- Remove your nosepiece and place in a container that will collect the water.
- Remove the humidifier.
- Attach your oxygen tubing directly to your oxygen concentrator. This will help eliminate the water from your oxygen tubing.
- When your oxygen tubing is dry, reattach your humidifier.

Unit not operating (power failure alarm sounds):

If your power failure alarm sounds, check to see that:

- Plug is securely in outlet.
- You have pressed the reset button.
- You have power.

Unable to dial prescribed flow rate:

If you have an obstruction in your oxygen tubing, the alarm on your machine will sound, and the flow meter will fall to zero. If this occurs:

- Disconnect tubing and check for nicks in tubing and nosepiece.
- Replace tubing and check to see if flow rate is restored.

INCLEMENT WEATHER/DISASTER INFORMATION

A disaster is an emergency situation that will result in interruption of your services.

Power Outage

In case of a power outage, if you require assistance and our agency phone lines are down, do the following:

- If you are in a crisis or have an emergency situation, call 911 or go to the nearest hospital emergency room.
- If it is not an emergency, but you need assistance, call your closest relative or neighbor. Our agency will get in touch with you as soon as possible.

Flood/Hurricane

Floods are the most common and widespread of all natural hazards. Some floods can develop over a period of days, but flash floods can result in raging waters in just a few minutes. Be aware of flood hazards, especially if you live in a low-lying area, near water or downstream from a dam.

Assemble a **disaster supply kit**. Include a battery-operated radio, flashlights and extra batteries, first aid supplies, medications, extra oxygen, sleeping supplies and clothing. Keep a stock of food and a three-day supply of extra drinking water.

If local authorities issue a flood watch, prepare to evacuate by:

- Securing your home. Move essential items to the upper floors of your house.
- Turning off utilities at the main switches or valves, if instructed. Do not touch electrical equipment if you are wet or if you are standing in water.
- Cleaning the bathtub and filling it with water in case your locality's supply becomes contaminated or water services are cut off.

If there is a flood:

- Do not walk through moving water. Six inches of moving water can knock you off your feet. If you must walk in a flooded area, walk where the water is not moving.
- Use a stick to check the firmness of the ground in front of you.

Tornado

Tornados are nature's most violent storms. When a tornado has been sighted, go to your shelter immediately. Stay away from windows, doors and outside walls.

In a house or small building:

- Go to the basement or storm cellar. If there is no basement, go to an interior room on the lower level (closets, interior hallways).
- Get under a sturdy table, hold on and protect your head. Stay there until the danger has passed.
- If the patient is bed-bound, move the patient's bed as far away from windows as possible. Cover the patient with heavy blankets or pillows, being sure to protect the head and face. Then go to a safe area.

In a nursing home, hospital, or shopping center:

- Go to predesignated shelter areas. Interior hallways on the lowest floor are usually safest. Stay away from windows and open spaces.

In a high-rise building:

- Go to a small, interior room or hallway on the lowest floor possible.

In a vehicle, trailer or mobile home:

- Get out immediately and go to a more substantial structure. Do not attempt to out-drive a tornado. They are erratic and move swiftly.

If there is no shelter nearby:

- Lie flat in the nearest ditch, ravine or culvert with your hands shielding your head.

Lightning

Inside a home, avoid bathtubs, water faucets and sinks because metal pipes can conduct electricity. Stay away from windows. Avoid using the telephone, except for emergencies. If outside, do not stand underneath a natural lightning rod, such as a tall, isolated tree in an open area. Get away from anything metal, including farm equipment, bicycles, etc.

Winter Storms

Heavy snowfall and extreme cold can immobilize an entire region. Even areas that normally experience mild winters can be hit with a major snow storm or extreme cold. The results can range from isolation due to blocked roads and downed power lines to the havoc of cars and trucks sliding on icy highways. To prepare for winter storms, gather emergency supplies such as:

- A battery-powered radio.
- Food that doesn't require cooking.
- A manual can opener.
- Your medications.
- Extra blankets.
- Extra water in clean soda bottles or milk containers.
- Rock salt or sand to melt ice and improve traction.
- Flashlights, battery-powered lamps and extra batteries (candles are a fire hazard).
- Make sure you have enough heating fuel; regular fuel sources may be cut off.
- Extra oxygen tanks.

Dress for the season:

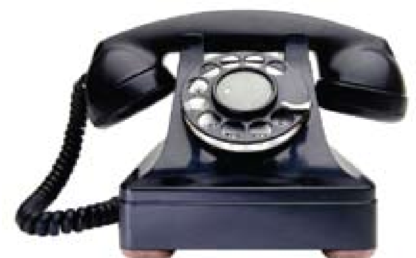
- Wear several layers of loose-fitting, light-weight, warm clothing rather than one layer of heavy clothing. The outer garments should be tightly woven and water repellent.
- Mittens are warmer than gloves.
- Wear a hat: most body heat is lost through the top of the head.

Disaster Preparedness Plan For Patients and Families

- Keep an emergency kit in the home that contains:
  - — Portable radio with batteries.
  - — Cigarette lighter.
  - — Flashlight and batteries.
  - — Kerosene or battery powered lantern.
  - — First aid kit.
- Listen to weather updates on storm's approach.
- Check medication regularly to be sure you have an adequate supply in the event of an emergency.
- Have a plan for emergency heat.
- If you have to leave your home due to an electrical outage:
  - — Notify hospice.
  - — Take all your medications with you.
  - — During bad weather, your hospice nurse will be calling to maintain contact.
- Always call your home medical equipment supplier before you need to connect your last tank of oxygen during a power outage so they have plenty of time to make additional deliveries if road conditions are bad.
- Nurses may not be able to visit when road conditions are dangerous, but advice and instruction may be given by phone. Emergency situations will be taken care of in the safest manner possible.

Emergency Phone Numbers

- **Police and Fire (all cities):** **911**
- **Dominion Power (all cities):** **1-888-667-3000**
- **Virginia Natural Gas (all cities):** **1-877-572-3342**
- **Non-emergency numbers to assist with moving patients:**
  - — Chesapeake: 757-382-6161
  - — Franklin: 757-562-8575
  - — Hampton: 757-727-6111
  - — Newport News: 757-247-2500
  - — Norfolk: 757-441-5610
  - — Portsmouth: 757-393-5300
  - — Smithfield: 757-357-3247
  - — Suffolk: 757-923-2350
  - — Virginia Beach: 757-375-5000
  - — Williamsburg: 757-259-7210
  - — Yorktown: 757-890-3630



INFECTION CONTROL AT HOME

Cleanliness and good hygiene help prevent infection. Contaminated materials such as bandages, dressings or surgical gloves can spread infection and harm the environment. If not disposed of properly, these items can injure trash handlers, family members and others who could come in contact with them.

Certain illnesses and treatments (i.e. chemotherapy, dialysis, AIDS, diabetes, burns) can make people more susceptible to infection. Your nurse will instruct you on the use of protective clothing (gowns/gloves) if they are necessary.

Notify your physician and/or home care staff if you develop any of the following signs and symptoms of infection:

- Pain/tenderness/redness or swelling of body part
- Inflamed skin/rash/sores/ulcers
- Painful urination
- Confusion
- Nausea/vomiting/diarrhea
- Fever or chills
- Sore throat/cough
- Increased tiredness/weakness
- Pus (green/yellow drainage)

You can help control infection by following these guidelines:
Wash your hands before and after giving any care to the patient (even if wearing gloves), before handling or eating foods, and after using the toilet, changing a diaper, handling soiled linens, touching pets, coughing, sneezing, or blowing nose. Hand washing needs to be done frequently and correctly. **Washing your hands is the single most important step in controlling the spread of infection.**

Suggested steps to proper hand washing include:

- Remove jewelry and apply warm water and soap (liquid soap is best) to the hands
- Hold your hands down so water flows away from your arms
- Scrub for at least 10-15 seconds (30 seconds is recommended) making sure you clean under your nails and between your fingers
- Dry your hands with a clean paper towel, and use a new paper towel to turn off the faucet.
- Apply hand lotion after washing to help prevent and soothe dry skin.
- If hands are not visibly soiled, you may use an alcohol-based solution. Rub all over hands and between fingers until dry.

Disposable Items and Equipment

Disposable items are non-sharp and may be disposed of in the regular trash. Examples include paper cups, tissues, dressings, soiled bandages, plastic equipment, urinary/suction catheters, disposable diapers, Chux, plastic tubing, medical gloves, etc.

Be sure to store medical supplies in a clean/dry area. Dispose of used items in waterproof (plastic) bags. Fasten securely and dispose of bag in the trash.

Non-Disposable Items and Equipment

Items that are not thrown away include soiled laundry, dishes, thermometers, commodes, walkers, wheelchairs, bath seats, suction machines, oxygen equipment, mattresses, etc.

Soiled laundry should be washed separately from other household laundry in hot, soapy water. Handle these items as little as possible to avoid spreading germs. Household liquid bleach should be added if viral contamination is present. **Suggested bleach solution contains one part bleach to ten parts water.**

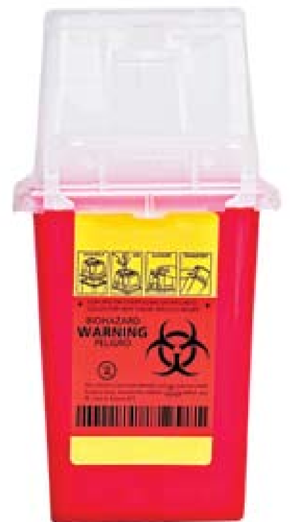
Equipment used by the patient should be cleaned immediately after use. Small items (except thermometers) should be washed in hot, soapy water, rinsed and dried with clean towels. Household cleaners such as disinfectant, germicidal liquids or diluted bleach may be used to wipe off equipment. Follow equipment cleaning instructions and ask your nurse/therapist for clarification. Thermometers should be wiped with alcohol before and after each use. Store them in a clean, dry place.

Liquids may be discarded in the toilet. Clean the container with hot, soapy water, rinse with boiling water and allow to dry.

Be sure to wash your hands after handling soiled equipment!

Sharps Objects

Sharps items include needles, syringes, lancets, scissors, knives, staples, glass tubes or bottles, IV catheters, razor blades, disposable razors, etc.



Place used "sharps" directly into a clean, rigid container with a screw-on or tightly secured lid. Use a hard plastic or metal container. Before discarding a container, reinforce the lid with heavy-duty tape.

NEVER overfill the container or recap needles once used. **DO NOT** use glass or clear plastic containers, and never put "sharps" in containers that will be recycled or returned to a store. Seal the container with heavy-duty tape and place in the trash can or dispose of according to local regulations.

Spills In The Home

Spills that contain blood and other body fluids are cleaned by putting on gloves and removing fluid with paper towels. Use a cleaning solution of household bleach and water *(1 cup of bleach to 10 cups of water)* to wipe the area again. Double bag the used paper towels and dispose of in the trash.

Medical Emergency

An on-call nurse is available after office hours to answer questions and make home visits if needed. **Many emergencies may be resolved by calling HOSPICE FIRST.**

MEDICATION

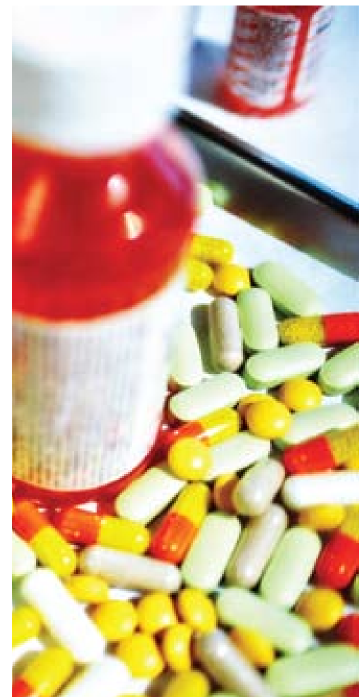
Medications are an important part of the care of the hospice patient. A notebook is helpful to write down when medications are to be given and their effect. Other tips for handling medications safely include:

- Keep a current list of all medications, including over-the-counter medications. Take the list with you on all physician and hospital visits.
- Keep the list with the medications in a box in a safe place. (A plastic box or shoebox is a good size container).
- Keep medications in their original container.
- Keep all suppositories (medications to be given by rectum) in the refrigerator.
- Keep Tylenol or generic brand in pill or suppository form available for unexpected fever at night.
- Keep your thermometer in your medication box.
- Keep refills updated. Your physician may not be on call if you run out after hours.
- Keep old or discontinued medications in a separate container. Do not destroy them as they may be needed at a later time.
- **Symptoms can be controlled more easily if treated early. Write on each medicine bottle what it is FOR if the pharmacist has not already done so.**

Do NOT:

- Store medications in the bathroom where humidity is high.
- Crush or break medications without discussing with the hospice nurse. Many medications are coated for delayed action, and crushing will destroy that action.

Proper Disposal of Prescription Drugs



- Take unused, unneeded, or expired prescription drugs out of their original containers and throw them in the trash.
- Mixing prescription drugs with an undesirable substance, such as used coffee grounds or kitty litter, and putting them in impermeable, nondescript containers, such as empty cans or sealable bags, will further ensure that drugs are not diverted.
- Flush prescription drugs down the toilet only if the label or accompanying patient information specifically instructs doing so.
- Take advantage of community pharmaceutical take-back programs that allow the public to bring unused drugs to a central location for proper disposal. Some communities have pharmaceutical take-back programs or community solid-waste programs that allow the public to bring unused drugs to a central location for proper disposal.
- If swallowing is difficult, tell your nurse. The medication can be changed. Liquids, patches or suppositories may be ordered.

PAIN

One of the first questions often asked after hearing the diagnosis of a life-limiting and progressive illness is, “Will I suffer?” This question automatically produces fear and anxiety. **Pain control with improved quality of life is a primary goal for the patient, the caregiver and the hospice team.**

Each person views pain differently. Some feel pain is inevitable and something they must bear. Others are afraid to admit that the pain is increasing as a sign of rapid progression of the disease. Some are fearful of addiction to medication.

It is important to recognize and talk about how pain is experienced and expressed.

- Is the pain restricting movement?
- Is the pain resulting in shallow, restricted breathing?
- Is the pain causing depression and withdrawal?
- Is the pain expressed as tension or irritability?
- Is the face tight, with the brow furrowed?

Pain Medication

Addiction should not be considered in pain management of the patient with life-limiting and progressive illness. Addiction occurs when narcotics are used for psychological and emotional reasons. Your physician and primary nurse will be glad to discuss any questions you have regarding use of narcotics.

Side effects may occur with the use of any medication. These may include dry mouth, increased heart rate, constipation, drowsiness, nausea and vomiting. Report all side effects to your primary nurse.

Giving pain medicine:

- If nausea has been a problem, offer prescribed nausea medication with a little water ½ to 1 hour before pain medicine.
- Roll the head of the bed up or position the patient with pillows.
- Moisten the mouth before offering the medication.

Suggestions for management of side effects may include:

- **Dry mouth:** Frequent fluids, hard candy or gum, use of artificial saliva.
- **Increased heart rate:** May decrease within a few days of starting medication or changing dosages.
- **Constipation:** See section on constipation. Watch for increased constipation with increase in pain medication.
- **Drowsiness:** Usually subsides within 1-3 days of starting or increasing dosage of medication.
- **Nausea and vomiting:** Note if this occurs with each dosage. Notify the nurse, and a change in medication will be discussed with your physician.

Non-narcotic pain relievers such as Ibuprofen or antidepressants may be ordered for "bone pain" or "nerve pain." These are to be used with other pain medication to decrease specific symptoms of the disease process. Their effect is not immediate and may be seen as ineffective. These medications are to be taken regularly for the desired effect.

Narcotics are most effective if taken on a regular schedule. A long-acting medication is usually ordered to avoid the "up and down" response to pain. Waiting until the pain is "bad enough" before taking the medication is an ineffective approach to controlling pain.

A second, more rapid-acting medication may be ordered for breakthrough pain. (Sudden or occasional pain, unrelieved by the long-acting medication). Keeping a record of how often the rapid-acting medication is needed will alert the physician and nurse to re-evaluate the need to increase the long-acting medication. Sudden, severe pain may occur and be frightening for both the patient and the caregiver. This may occur late in the evening or at night. Give the ordered amount of medication for breakthrough pain. If unrelieved after 45 to 60 minutes, call the hospice nurse. The nurse can make suggestions for added pain control and comfort measures.

Remember, patients who have lived with pain may not show the same signs of pain or complain the same way as someone who is suddenly experiencing pain. Watch for:

- Decreased activity and movement
- Short, rapid breathing
- Stiffness or tenseness of the body
- Furrowed brow and tight facial muscles
- Resistance to being turned or repositioned

NOTE: The above signs may also be observed during sleep or if the patient is in a coma.

Your physician may order medication for anxiety or restlessness. These medications may be given in combination with pain medication to offer a more rapid response to pain relief. The hospice nurse will review the medication and advise you in administering these medications in times of uncontrolled pain.

Relaxation, Breathing and Imagery Exercises

Pain causes the body to tense, and in turn the body may experience increased pain. Breathing may become shallow and rapid. Often patients find relaxation breathing helpful, especially with a sudden increase in pain and awaiting relief after taking pain medication. It may be helpful for another person to read the exercises to the patient. You may want to ask your nurse or social worker to help with these exercises.

- Close your eyes and take a long, slow, deep breath. You may wish to sigh as you breathe out. Concentrate on breathing slowly and deeply for several seconds. Mentally repeat a phrase with each breath such as (breathe in) "I am" (breathe out) "relaxing." (Breathe in) "My pain" (breathe out) "is decreasing." Or, if you find comfort in your faith (breathe in) "God is" (breathe out) "love." Continue to concentrate on the breath and feel your body relax and sinking into a chair or bed. Stop the exercise at any point by slowly telling yourself, "It is time to open my eyes." Slowly open your eyes.

- Close your eyes and breathe in a long, slow breath. Feel the air moving into your lungs. As you breathe out, feel the air move to the point of pain and exit at that point as if the breath is moving the pain out of the body. Continue the exercise as long as needed to feel the relaxation of the area of pain. End the exercise by telling yourself it is time to open your eyes and slowly do so.

- Close your eyes and breathe deeply and slowly. Imagine an object you consider beautiful: a rose, a tree, a mountain or stream. Picture the object far away and bring it closer until you can see very small details such as the petals, the branches, and leaves, or the smell of the earth or the feel of water. Continue to breathe slowly and deeply. Surround yourself with the beautiful object. If your mind goes back to the pain, it is OK, just focus again on the object and breathe slowly and deeply. End the exercise by telling yourself it is time to leave the object and slowly open your eyes.

- Close your eyes and breathe deeply and slowly. Imagine yourself walking under large trees. The air is clear and fresh. Breathe in the air. You walk to a clearing and you look around to see a beautiful place. Imagine whatever is beautiful to you: your backyard, the beach, a mountaintop. See the color of the sky or imagine animals, plants, water, or the air that surrounds you. You are there and filled with love and peace. Breathe slowly and deeply. Enjoy every detail of the special place and know you can visit as long as you want. End the exercise by telling yourself it is time to leave and slowly leave and open your eyes.

Heat And Cold

Heat and cold applications, such as heating pads and ice packs, may be used for 15-30 minutes over the areas of pain. Always use a cotton cloth between the source of heat or cold and the skin. Check the skin frequently. Avoid use of the highest setting on heating pads or use of heating pads during sleep.

General Comfort

Comfort may also be increased by:

- Changing the body position. Don't sit or lie in one position for more than two hours.
- Use pillows under arms, feet and legs.
- Provide a pleasant view of a plant, flowers, or favorite things. Open curtains or blinds for added light.
- Also provide clean fresh sheets, a tidy room and a calendar and clock to keep track of the day and time.
- Wash face and hands throughout the day.
- Apply lotions to soothe the skin.
- Share a loving touch.

NUTRITION AND EATING

One of the most common problems with life-limiting conditions is loss of appetite. Taste changes, nausea and vomiting, depression, and the dying process all contribute to the lack of interest in food. This is very frustrating for caregivers. It is painful to watch loved ones waste away.

The body wants and needs food for energy. **As the body prepares for death, food and drink are the first things it gives up.** This is a natural process and should be expected. At times, patients may give up all food and drink for days (for even 2 weeks before death occurs).

Continue to offer food and fluids frequently, but remember, this is all you can do. **Trying to force food or constantly talking about how little the patient is eating will only add to your stress and the patient's.** A dietician may be asked to help for special nutritional problems.

HINTS TO STIMULATE EATING:

- Avoid extremes in temperature of foods.
- Prepare foods in the morning or use good ventilation. Strong cooking odors may increase nausea.
- Use small plates and glasses.
- Offer small glasses of a variety of favorite juices or drinks that contain calories and nutrition.
- Keep a variety of high-nutrition food on a small plate for the patient to snack on.
- Stay calm if favorite foods are refused (patients may ask for special food then eat only one or two bites).
- Offer small portions frequently.
- If taste is decreased, sweet or tart foods and the addition of herbs or agreeable spices may help.
- Make food and mealtime as attractive and pleasant as possible.

Dry mouth:

- Tart foods such as lemon custard may stimulate saliva.
- Sip on fruit juices.
- Use foods high in water content (well-cooked vegetables, canned fruits, gravies or sauces).
- Suck on hard candy or Popsicles.
- If severe, discuss with your nurse. A saliva substitute may be needed.

NAUSEA AND VOMITING

Nausea with or without vomiting is unpleasant but can be controlled by the following.

Look for the cause:

- The disease itself.
- Constipation.
- Radiation or chemotherapy.
- Pain medication (write down when nausea begins after taking medication).
- Medicine taken on an empty stomach.

Correct the cause if possible:

- Take medication to relieve symptoms on a regular schedule, 45 minutes before eating or drinking, beginning early in the day.
- Avoid foods that seem to trigger nausea.
- Eliminate unpleasant odors.
- Avoid cooking strong-smelling foods without good ventilation.
- Brush the teeth and tongue frequently during the day.
- Offer Popsicles, Jell-O or frozen Kool-Aid.
- Avoid excessive sweets or fatty foods.
- Sip cool, clear fluids.
- Eat toast or crackers and progress to small meals.
- Avoid constipation.
- Take nausea medication 45 minutes prior to taking laxative.
- Drink more fluids after nausea medication has taken effect.

Pain medication:

Write down when nausea begins after taking medication.

Report to the hospice nurse:

- If nausea and vomiting occur only in the morning, offer crackers or toast 20-30 minutes before regular medications are given. If the patient takes a large number of daily medications in the morning, the hospice nurse may suggest giving some later in the day.
- Offer attractive "light" foods such as fruits or salads and avoid "heavy" foods that contain gravy or cheese during times of nausea.

BREATHING

Congestion or shortness of breath may occur. This may be frightening to the patient and the caregiver. With less activity and longer periods in bed, breathing becomes shallower, and secretions may pool in the lungs and throat. Uncontrolled pain may also limit lung expansion.

HINTS:

- Be calm.
- Raise the head of the bed or position on pillows unless there is excessive swelling of the abdomen.
- Encourage slow, deep breathing. (Demonstrating the following procedure may help the drowsy or confused patient). Fill the lungs until the abdomen protrudes and exhale with force 4 to 5 times. Follow with 2 to 3 coughs. Repeating several times every 2 hours while awake usually will lead to marked decrease in congestion.
- Encourage turning every 2 hours (more often if needed) to allow gravity to drain the lungs. (Lower the head of the bed).
- Increased fluid intake will thin lung secretions.
- Avoid milk and milk products during periods of congestion as these cause thickening of secretions.

Report to the hospice nurse:

- Increased congestion or shortness of breath.
- Changes in skin color.
- Changes in breathing patterns.

Oxygen Use

Oxygen may be ordered for shortness of breath for some patients. An oxygen concentrator and a back-up tank of oxygen will be delivered by the medical equipment company. They will instruct you in its use.

- Oxygen may not help certain types of breathing patterns due to the patient's medical condition or disease process.
- Mouth breathing does NOT decrease the amount of oxygen received through nasal tubing.
- Too much oxygen may cause headache, slurred speech and slow breathing.
- **Oxygen does not lessen the need to encourage deep breathing, coughing and turning.**

Safety:

- Call your power company and tell them oxygen is being used in he home. They will be alerted to the need for priority repairs.
- Display the Oxygen Alert Notices.
- Follow the safety instructions supplied by the equipment company.
- Wash your hands prior to cleaning humidifier or tubing.
- Know how to connect the oxygen tank in the event of power failure and call the equipment company for additional tanks of oxygen.
- Call for additional tanks of oxygen before you connect the last tank.

Breathing Comfort

- Apply a water-soluble lubricant (not petroleum jelly) for dry or cracked nostrils.
- Use cotton to ease pressure around ears or face.

Report to the hospice nurse:

- Increased difficulty breathing.
- Restlessness, anxiety or irritability.
- Blueness of lips or nail beds.
- Confusion or difficulty with concentration.

Points to remember:

- Suctioning may stimulate coughing or gagging.
- Encourage the patient to deep breathe slowly several times before inserting the tip of the suction wand into the mouth or to the back of the throat.
- Don't leave the suction tip in the mouth for more than 8 – 10 seconds.
- Dip the tip in a glass of water to clear the tubing between suctions.
- Allow the patient to rest and encourage the patient to take deep, slow breaths between suctions.
- Report to the hospice nurse if the patient has a large amount of secretions or the secretions are frothy or pink.
- Wash the collection container after use and keep a glass of fresh water available for the next suctioning.

SKIN AND MOUTH CARE

Daily Skin Care

- Keep the skin clean and dry.
- Avoid over-padding the foam mattress.
- Use a flat sheet folded in half or quartered under the trunk of the body to turn and position patient.
- Smooth wrinkles from sheets.
- Massage red areas.
- Turn patient every 2 hours or remind patient to turn.
- Use pillows to support arms, legs and back.
- Use lotions containing lanolin to replace moisture loss due to less fluid intake.
- Report all changes in the skin to the hospice nurse.

Excessive perspiration may or may not follow a fever. Change pajamas and sheets as needed. Wipe the skin with a cool cloth, dry and turn the patient frequently to provide comfort and reduce skin irritation. Combing damp hair away from the face and turning the damp pillow is another comforting measure.

Frequent mouth care may help improve the taste of food and fluids. Use of a soft toothbrush or a soft cloth wrapped around a finger provides the best cleaning action. Disposable, foam-covered sticks may also be used, but a toothbrush dipped in warm water will do a better job of cleaning the teeth, gums and tongue.

Changes in the skin are often a concern of the patient and the caregiver. Early recognition and prevention of problems are key factors. Look for the cause. Decreased appetite, fluid intake and mobility could be the cause.

Correct the cause if possible:

- Offer more fluids. Juices and vegetable drinks provide vitamins and minerals.
- Offer foods high in vitamins and avoid those low in nutritional value.
- Examine the body daily for blisters, red areas, cracks or tears.
- Report the first signs of breakdown to your primary nurse.

Pressure areas or "bed sores" develop rapidly. Use the following example to understand how this breakdown of the skin occurs. Place a clear glass or plate on your fingertip. The weight of the object blanches or forces the blood out of the fingertips, just as the weight of the body presses against the bed. The blood, which carries oxygen to skin tissues, cannot move freely, so the skin begins to break down.

Daily Mouth Care

- Remove dentures regularly for cleaning.
- Weight loss may require relining of dentures to avoid rubs and abrasions.
- Frequent antibiotic use can cause loss of “good” bacteria and lead to thrush, a condition that causes soreness and white patches in the mouth. Eating yogurt daily will replace the “good” bacteria.
- Keep lips moist with use of lip balm.

Sore mouth:

- Report to your primary nurse for treatment.
- Avoid salt or tart foods, crackers or hard foods that may cut or rub sore areas, extremely hot or cold food or drink.
- Eat regular or frozen yogurt daily to replace normal bacteria if thrush is present.

Report to the nurse:

- Sore mouth.
- White patches in the mouth.

ELIMINATION

Changes in urination and bowel movements can be embarrassing and frustrating for the patient and the caregiver. It often is viewed by the patient as a loss of control, not only of their body functions but also of their life. They realize that they must ask for help with every aspect of their life. A matter-of-fact but caring attitude by the caregiver lessens this feeling of helplessness.

Use of a bedside commode, bedpan or urinal will be needed as weakness increases. A catheter may be inserted for urinary incontinence or the inability to urinate. Incontinence pads or briefs are available to protect the patient and the bed from soiling.

TIPS:

- Offer as much privacy as possible while maintaining patient safety.
- Use powder on the edges of the bedpan.
- Raise the head of the bed while the patient is on the bedpan.
- Keep ½ to 1 inch of water in the bedside commode (a few drops of dish detergent in the water decreases soiling and makes rinsing easier).
- Rinse urinal twice between use and keep within the patient's reach.
- Notify hospice if the patient is unable to urinate for 12 or more hours or if the lower abdomen is swollen or painful.
- Dark, small amounts of urine may occur. Offer fluids frequently, along with foods high in water content, such as fruits.
- Record bowel movements and report hard or painful stools.

Constipation

Changes in bowel elimination will occur, with illness causing discomfort, embarrassment and frustration. Early intervention is the key to avoiding this common problem.

Look at the cause:

- Changes in diet
- Decreased physical activity
- Decreased fluid intake
- Medications

Correct any cause that can be corrected:

- Offer more fruit and fiber. High-fiber foods will not decrease constipation without adequate fluid intake.
- Increase fluid intake, especially apple juice and water.
- Avoid foods that may be constipating, such as cheese, peanut butter and bananas (these may vary with individuals).
- Keep a record for 2 days to get a clearer idea of how much the patient drinks.
- **Do not decrease pain medications to avoid constipation. A natural stool softener and laxative can be ordered and increased as pain medication is increased.**

The following procedures are suggested for unrelieved constipation:

- Give the patient 2-4 tablets of Senokot-S (if ordered by your physician) each morning and night. Remember that fluids are needed to aid the effectiveness of all laxatives.
- If no bowel movement in 48 hours, notify your primary nurse. She will advise you in additional measures to take.

Enema

An enema may be needed if the patient is constipated and cannot pass the stool. Your nurse can advise you in the type of enema to obtain.

- Protect the mattress if the patient is not using a hospital bed. A plastic shower curtain liner works well under the sheets.
- Gather the following supplies: incontinence pads, bedpan or bedside commode, toilet tissue and wash cloths, enema, gloves, and lubricant if using an enema bag.
- Place incontinence pads under the hips. Have the patient turn to the left side with the right knee bent. (This position allows the solution to drain into the bowel.)
- Lubricate the enema tip if not using a disposable enema that is pre-lubricated.
- Ask the patient to breathe slowly and deeply through the mouth.
- Insert the tip of the enema bottle into the rectum and squeeze slowly and gently.

If most of the solution begins to run out of the rectum, remove, wait a few minutes and reinsert:

- Ask the patient to squeeze the rectum during the insertion of the tip and after its removal to hold the solution in the rectum for 5 – 15 minutes. This is often very difficult for a weakened patient. They may need a second enema to stimulate the bowel enough to expel the stool.
- Help the patient onto the bedpan or bedside commode.
- Wash your hands and the patient’s hands after cleansing the rectal area.

Hard, dry stool may scratch or irritate the rectum and bowel. Do not be alarmed if a small amount of bleeding occurs. This usually stops within minutes after the stool is expelled. If bleeding continues, tell your hospice nurse.

Diarrhea

Frequent, watery stools (often with abdominal cramping) may cause problems for the patient. Your primary nurse will help identify the cause. Review all the facts with your nurse before offering medications for diarrhea. Forceful liquid stools may signal a bowel impaction if the patient has been constipated or has had small, hard stools. Occasionally the patient may be sensitive to a daily laxative/stool softener. A change in the dosage is more effective than stopping the medication or giving another medication.

- Offer more fluids frequently. Avoid caffeine in coffee, tea and soft drinks.
- Review food intake and avoid foods known to stimulate the bowels (excessive intake of fruits or fruit juices, greens, milk or milkshakes, nuts, corn).
- If diarrhea occurs for more than 2 hours, discontinue food and offer only small amounts of fluids.
- Clean the rectal area and wash your hands and the patient’s hands after each stool.
- Report blood (red or black) or blood odor.
- Notify your hospice nurse.

CATHETER CARE

A catheter may be inserted to empty the bladder continuously. It is held in place by a small balloon inflated at the end of the tubing.

Daily Care

- Avoid tugging or pulling on the tubing.
- Wash around the tubing 1 or 2 times a day with warm, soapy water. Rinse and dry.
- Keep the drainage bag below the level of the bladder.
- Avoid touching the tip of the drainage bag when emptying.
- Avoid resting the drainage bag on the floor.

Report to the nurse:

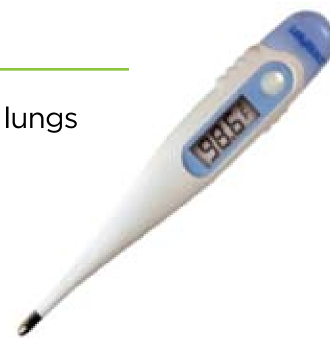
- Strong urine odor. Offer more fluids.
- Urine not draining.
- Urine leaking around tubing.
- Blood in urine.
- Pain and fullness in the lower abdomen.
- Catheter accidentally comes out. Look for bleeding if balloon is still inflated.
- Dark, scant amounts of urine may signal dehydration. Offer fluids frequently, along with foods high in water content, such as fruits.

Irrigating the Catheter:

Your physician may order irrigation of the catheter if the catheter becomes blocked. Your primary nurse will teach you how to irrigate the catheter and will provide needed equipment.

- Wash hands well and put on gloves.
- Place a waterproof pad under the catheter.
- Pour about ½ cup irrigating solution into container.
- Keep the cover on the tip of the syringe and in the tray until filling the syringe.
- Separate the catheter from the drainage bag tubing.
- Insert the syringe bulb into the catheter.
- Gently squeeze the bulb to push the fluid into the catheter. The fluid should go in easily without force.
- Repeat procedure if instructed to do so by your nurse.

FEVER



Unexplained fever may occur at any time. The first areas to question are lungs and bladder.

Is there a cough? Has the patient been in bed more? Is breathing more shallow? Has fluid intake decreased? Follow instructions given under "Breathing" and notify the hospice nurse.

Is the urine dark and of scant amount? Has the odor changed? Has the fluid intake decreased? Does the patient have a catheter? Notify the hospice nurse, and encourage the patient to increase fluid intake.

Anticipate fever and ask your hospice nurse what to keep on hand. Fever often occurs more at night and during periods of nausea and vomiting. Suppositories are helpful during these periods and should be kept refrigerated.

DO:

- Have a thermometer available.
- Offer medication for fever as instructed (usually Tylenol or generic form).
- Keep Tylenol (pill and suppository form) available.
- Remove all bed covers and heavy clothing.
- Bathing with cool or tepid water may help reduce fever more rapidly.
- Change clothing as it becomes damp from perspiration. Once perspiring begins, the fever will usually begin to subside.
- Offer fluids frequently. The body may lose excessive amounts of fluid.

DO NOT:

- Offer aspirin or anti-inflammatory medications such as Advil or Ibuprofen for fever unless you have discussed this with your nurse or physician.
- Offer excessive cold drinks if the patient is having chills.

DIABETES CARE

The patient with diabetes may experience difficulty regulating their blood sugar due to decreased appetite, weight loss or other symptoms associated with this life-limiting illness. Your physicians and primary nurse will help monitor the need for changes in medications for regulating "sugar" in the blood. Follow instructions from your physician for when to administer or withhold insulin.

The following can help you take action before symptoms become severe, in order to avoid an unplanned trip to the emergency room. **Check the patient's blood sugar if you have a blood sugar monitor.**

Low Blood Sugar

Symptoms usually come on FAST:

- Excessive sweating
- Headache
- Irritability
- Slurred speech
- Trembling
- Blurred vision
- Pounding heart
- Hunger
- Unable to awaken
- May act "drunk"

Action to take if awake:

- Give candy, soft drink or orange juice. Usually the symptoms start to disappear within minutes.
- Follow with crackers with peanut butter or a sandwich and milk. These foods break down more slowly into sugar.
- Call the hospice nurse.

If unable to swallow or if "asleep" and unable to awaken:

- Turn patient on side and put 1/2 to 1 teaspoon of honey inside the check. Rub cheek lightly to smear honey over a larger surface. If the patient has frequent low blood sugar, purchase a small tube of cake icing. This is convenient to carry and can be squirted into the cheek of a sleeping or unconscious patient.
- Call the hospice nurse. Usually the patient will awaken within minutes.
- Follow with foods after the patient is fully awake.

Possible reasons for reaction:

- Too much Insulin.
- Not eating enough.
- Vomiting.
- Not eating soon enough after.
- Taking Insulin.
- Increased activity.

High Blood Sugar

Symptoms usually come on SLOWLY:

- Increased urination.
- Increased thirst.
- Stomach pains.
- Deep breathing.
- Loss of appetite.
- Nausea and vomiting.

Action to take:

- Give Insulin if patient has not had their daily injection.
- Give fluids without sugar.
- Call the hospice nurse.

Possible reasons for reaction:

- Too little Insulin.
- Eating too much or eating foods high in sugar.
- Disease, infections or fever.
- Emotional stress.

DEATH IN THE HOME

Patients often say within the last few days or hours of their life that they want to go home. Often they are in their own home, and they are speaking of their heavenly or spiritual home. **"Home"** has many meanings for the dying. The following are reasons some families have shared for choosing a home death:

- The patient feels wanted and loved.
- There is no fear of being alone when death occurs. Fear of being alone is one of the greatest fears of the patient.
- It is a safe and secure place to express feelings.
- The patient and caregiver can live by their own schedule.
- There is loving energy to surround the dying in the home.
- Familiar furniture and possessions offer memories of shared times.
- There are no limits on the number of visitors or the amount of time unless the caregiver or patient requests limits.
- Caregivers and loved ones rest more in the home.
- The patient does not have to be awakened for routines and procedures.
- The caregiver feels useful.
- The patient and caregivers can continue their regular eating habits.
- There is time to experience the final moments of life in the home and spend time with others who support you.
- There is enough time to say goodbye.
- There is dignity and respect.
- It is natural — it is **home!**

NEARING DEATH — EMOTIONAL CHANGES

- Months to weeks before death the patient may begin to withdraw. They are beginning to separate physically and emotionally from their loved ones. **Caregivers may feel helpless and begin their own grieving.**
- **We are never ready to give up holding the physical body. The realization of that day causes each of us to look within ourselves, and evaluate our lives together and apart. It is a time of preparation.**
- The patient may sleep more, or spend time with their eyes closed or staring into space. They may appear more irritable or lash out at loved ones. This is a normal reaction to fears and loss. It is a time of anger about unfulfilled hopes and dreams.
- Expressing emotions at this time is difficult. Just being close, holding a hand and saying, "I'm here for you" is all that is needed during periods of silence.
- As the body is preparing to separate from this world, so is the mind. At times when the eyes are closed or the faraway staring occurs, the patient may be getting a glimpse of their journey into another world, the world of soul and spirit. People of all countries and religions tell us about this special place.
- The patient may appear confused and speak in rambling speech and symbols. They talk of going home, planning a journey or getting in line. They converse with others we cannot see. They reach out for people and things we cannot feel.

Helpful Things You Can Do

- We cannot enter this other world, but we can share by listening to everything they say. The hospice team may be able to help you understand this near-death awareness the patient is experiencing. The team will also help you understand how this is different from hallucinations, a condition that occurs infrequently due to medications and is usually frightening and may include visions of bugs or feelings of persecution.
- This is a precious time to share with the dying person as you watch for clues: Does the rambling speech have a message? Does their vision bring a smile or look of wonder? Does the body seem to relax? Do they speak of beauty and light?
- Gentle statements or questions may let the dying know that you realize what is happening. They will feel that you understand and that you are giving them permission to tell you about this other world. "What do you see?" "Are you seeing someone who has gone on?" "What does it feel like?" "Is it beautiful, peaceful?" "Did they tell you anything?"
- Allow yourself to be open to their reality. If they seem frightened, reassure them, ask them about their experience and help them explore their feelings related to it.
- Do not try to "reason with them" or talk them out of their experience.
- Call your loved one by their name and gently remind them of who you are if they are confused.

NEARING DEATH — PHYSICAL CHANGES

Physical changes may be visible to the patient and caregiver soon after a diagnosis is made by the physician. Some changes may not occur until weeks or days before death. Some may never occur. **Each person's body is special and prepares itself in its own way for death.**

The following list of changes will help you understand the journey your love one's body is taking from the physical world to the spiritual world. You cannot take the journey with them or for them, but hospice will help you anticipate their care and comfort needs along the way.

Weeks or Months Before Death

General changes:

- Loss of appetite and thirst.
- Increased sleep.
- Emotional high and lows.
- Decreased physical activity.
- Spending more time away from others and talking less.
- Gradual lowering of blood pressure.
- Weight loss.
- Drenching perspiration of upper body with or without fever.
- If they are hot, place a sheet over them and/or gently wash their face, arms and legs with a cool cloth. Direct an electric fan toward them or open a window to circulate air if they continue to be hot.
- Cooling of arms and legs. If your loved one is cool to the touch, place a warm (not electric) blanket over them.
- Skin color becomes pale or bluish around the lips, ears and nails.
- Use lip balm to keep their lips moist.
- Occasional loss of control of bowel and bladder functions.
- Pain may increase or decrease.
- Eyes may appear not to see or become glassy.
- Difficulty swallowing.

Just as every birth experience is different and special for each person, so is this death experience. As more signs of death approach, your hospice team members will visit more often to help with physical and emotional concerns. This is a time to ask for support from friends and family and to allow yourself to lean on others. It is also a time to call in friends and family for last goodbyes.

The patient may be conscious until the time of death or gradually become unresponsive for days prior to death. **It is very important to remember that the patient's hearing usually continues even if the patient appears to be in a deep sleep or comatose state.** They will hear all of the important words you may still need to say:

- "I love you."
- "I'll miss you."
- "I know you are tired."
- "I will be okay."
- "It's all right for you to go."

Patients often hold on to this life until they feel their loved ones are ready to let them go. Frequently a restless, comatose patient with noisy breathing will relax and the breathing become quieter after loved ones have released them and told them they can go.

Changes in vision and speech:
Your loved one may now be more sensitive to light. Their eyes may be open, but unfocused and unseeing. It is as if they are looking through you at something beyond. Their eyes may fill with tears. They will talk less and eventually they may say only a word or two when spoken to. Their speech may become more difficult to understand. Eventually, they may not attempt to speak at all. As they move closer to the spiritual world, they have less need for words. Words belong to this physical world. They may communicate more with nonverbal communication, such as squeezing your hand, lifting a brow or smiling. A grimace or a furrowed brow can tell you they may be in pain.

- Dim the lights if they are sensitive to light.
- Reassure them that even though they cannot tell you, you know that they love you.
- Hold their hand and assure them that you are with them.
- Continue to give comfort medications as prescribed. Observe body language for signs of pain and distress.
- Talk to them even though they may not be able to respond to you verbally. Assume that they can hear you and understand what you are saying.

One to Three Weeks Before Death

- Your loved one will sleep much of the time.
- Call your loved one by their name and identify yourself to them even if they seem to be asleep.
- Always let them know what you are doing prior to providing care: "I'm going to turn you on your side."
- Sit by them and remind them that they are not alone.
- Breathing is not as deep and may be irregular. (The patient may appear not to breathe for short periods of time during sleep or rest.)
- Blood pressure continues to lower. The patient may get dizzy upon sitting or standing.
- The patient may experience increased or decreased pulse; drenching sweats, with or without fever; cooling of the arms and legs; changes in skin color (pale, yellow or bluish around lips, ears and nails); decreased control of bowels and bladder; increasing or decreasing pain; difficulty swallowing; refusal to eat or drink.
- Offer food and drink but do not force it.
- Offer food that doesn't require chewing, such as high-protein drinks to maintain your loved one's strength.
- Offer small amounts of food, and encourage them to eat and drink slowly.

- If they cannot swallow, use moistened swabs or small ice chips to keep their mouth and lips comfortable.
- Thicken liquids with a thickening agent, which can be found at the pharmacy. This can make your loved one less likely to choke on the liquid.
- Help them to sit upright while eating or drinking to decrease choking.
- Try using a lidded cup or a dropper. Avoid straws — they can cause your loved one to swallow air.
- **Give them permission to not eat or drink if they don't want to.** Sometimes they may force themselves to eat to satisfy loved ones, even if they don't want to.
- Continue to give comfort medications.
- Skin color in arms, feet and legs may have splotches or mottled areas of reddish blue or purple.
- May see or talk with people who have died (often relatives).

One or Two Days Before Death

- Eyes may appear glassy.
- Breathing and respiration changes.
- Breathing may stop for 15 – 45 seconds.
- Breathing may become loud and more irregular. Congestion may increase.
- Turn them on their side so that secretions can drain from their mouth.
- Remove the secretions from their mouth with a warm, wet washcloth or mouth sponge.
- Keep their lips moist with lip balm.
- Breathing may become very rapid or very slow.
- Restlessness and picking at clothing or bedding may occur.
- Reassure them that they are not alone.
- Do not try to restrain them, except to keep them safe.
- Try reading to them, playing soft music and talking to them about pleasant past experiences. Reassure them that it is all right for them to let go.
- Try repositioning them in bed.
- Change wet or soiled bedclothes and linens.
- Agitation can be caused by pain, so continue to give pain and comfort medications.
- Mottling or splotchiness moves from feet upward toward body.
- May continue to have contact with spiritual world.
- May speak in riddles or of events to come.
- May ask to go "home."

Signs of Imminent Death:

- Their lips, hands and feet may be bluish in color.
- Their arms, legs and feet may appear mottled.
- Their hands and feet may be cold to the touch.
- Their eyes may have a fixed, glassy stare.
- They may be breathing through their mouth with long pauses between their breaths.
- They may not respond to your voice.

WHEN DEATH OCCURS

- **Call hospice at the time of death at (757) 391-6017.**
- Depending on what time of day you call, a nurse will respond to your call.
- **Please try to keep the phone line clear until the nurse returns your call.**
- The death of someone in a hospice program, although an anxious event for family and friends, is not an acute medical emergency. While you should call the hospice, it is not necessary to call the medical examiner, the police or 911. When the death has occurred, take the time needed to call a supportive person or to adjust to the situation.
- There is no rush. Taking care of yourself is what is more important now.
- Depending on where the nurse is when you call, the nurse's arrival time to the home will vary. The nurse will let you know about how long it will take for him or her to get there.
- On arrival to your home, the nurse will assess the patient for vital signs such as heartbeat, pulse, breath sounds, and blood pressure. Once death is confirmed, the nurse will notify the physician and the funeral home of choice. The physician usually does not visit, nor is the patient's body taken to the hospital.
- While waiting for the funeral home personnel to arrive, the nurse may bathe and dress the patient in fresh clothing. The nurse may also remove any catheters, bandages or tubing from the body.
- The nurse will assist you in notifying other friends and relatives, including your minister.
- The nurse will remain with you until the funeral home personnel arrive to transport the patient's body to the funeral home. At that time, the funeral home representative will schedule a time with you to make final arrangements.
- When the body is removed from the home, some family members may want to view the removal of the body. Others may not. The choice is yours to make. Whatever you decide, the nurse will be there with you to offer support and assistance.
- You do not need to notify any authorities of the death. If required, the hospice nurse will notify them for you.
- Equipment companies will call in the following days to arrange a convenient time to pick up equipment.
- Medications should be destroyed as instructed by the hospice nurse.
- A hospice bereavement counselor will maintain contact with you through this time of grief by visits and phone calls for 13 months.

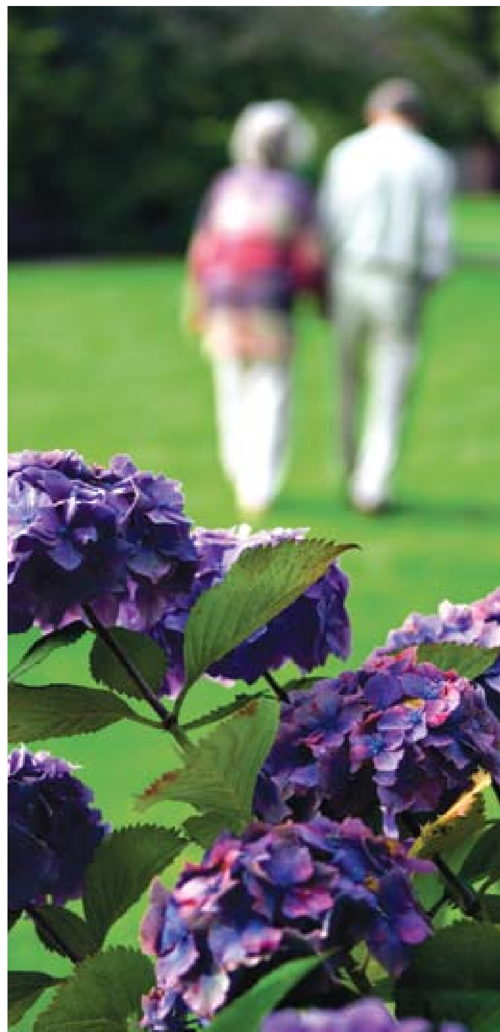
After the death of a loved one, you may also experience a closeness with the spirit of the loved one who has died. You may:

- Feel the loved one's presence in the room.
- Hear the loved one's voice give you comfort, advice or answers.
- Experience a spiritual moment of wonder or a closer connection to God.
- Awaken in the night and feel as if the loved one was by your bed.
- Question yourself if you feel you see your loved one while relaxing.

These experiences may happen a day, a week, or years after a death. They can be so real and powerful you may hesitate to share the experience. They are treasures loved ones give us. Share them with hospice.

GRIEF

Grieving usually begins soon after the diagnosis of a life-limiting illness is made. Patients grieve for the changes that are taking place within the body, for the loss of the ability to do things they can no longer do and for the shortened time they have with those they love. Loved ones also begin to grieve.



Grief is natural. It is our human response to change or loss. It is painful. How the pain of grief moves through the body, mind and soul is special to each person. You may question:

- "Why me?" "Why now?"
- "I can't believe this is happening."
- "Where is God?" "It can't be true."
- "I'm so empty, so numb."
- "I don't want to talk to anyone."
- "Is God punishing me?"
- "Why can't things just be the way they were?"
- "Where did I go wrong?"
- "My heart hurts." "I can't think."
- "I don't know what to do."
- "How can she leave me now?"
- "Someone should be able to fix this."
- "If the doctors and nurses had just done their job."
- "When will the pain go away?"
- "I can't cry." "I can't stop crying."
- "I hate what this is doing to me."
- "Why can't I say what I feel?"
- "What do I feel?" "I'm so tired."
- "I hate him." "What's the use?"
- "I keep getting a cold."
- "It hurts!" "It hurts!" "It hurts!"

Sometimes you don't know why you feel empty, hurt or sad. It helps just to say the feeling out loud to yourself and feel the feeling. Talk with someone, call the chaplain or bereavement counselor and say, "Help me understand these feelings. Where are they coming from?"

These emotions are powerful and sometimes frightening. Talk and cry with someone. Crying helps move the feelings through the body. **Tears are normal. Tears are precious.**

CHILDREN AND GRIEF

Children are often forgotten grievers. Faced with overwhelming circumstances, it is easier to believe that "the kids are doing fine" or "the kids can't really know what's going on." Because it is always difficult to watch children in pain (which we are forced to do once we admit that pain is present), adults often deny that a child's grief needs attention. **Children at all ages understand loss.**

The following may be helpful to children who are experiencing the life-limiting illness of someone they love:

- Tell them the truth, as you know it.
- Try to keep descriptions short, clear and to the point.
- Leave time for the children to ask questions. Ask for help from the hospice nurse, social worker, chaplain or bereavement coordinator if it is needed.
- Let children help. Children often want to protect adults just as adults want to protect children. Involve them as often as possible and as often as they will allow. Give clear instructions and let them know how helpful they are. Encourage them to continue to help.
- Help the child express feelings. Be aware that all expression of feeling is useful. It tells us what is and isn't working in a child's world and that they need something. It is communication.
- Help the child continue to play and talk and be with friends. They need a break from sadness, just as you do.
- Prepare the child for changes and new events. Whenever you can tell them about coming events, be clear.
- Know that you do not need to be your child's only support. Help the child build a support system made up of many different people (school counselor, youth pastor, neighbor, another family member, scout leader, etc.) This is very helpful and will also give you a needed break.

Things children can do:

- Change the water in a drinking glass.
- Share their school day with a bed-ridden person.
- Share memories ("Remember when …")
- Draw cheerful pictures or murals.
- Say "I love you"
- Give a hug.
- Do the dishes, clean their rooms, pick up their toys, run errands.
- Write letters or emails, or make phone calls.

_______________ (name) thank you for all you have given me, your family, friends and the world. You have impacted my life with your love, your caring and your wisdom. Now that you are gone, I will carry all your love and everything I learned from you within me. The essence of who you were as a person will live within me. The essence of who you were as a person will live within me and within others. You will continue to give to the world as we pass on to others what we learned from you. I will miss you, but will have joy in remembering all you meant to me. Each thing you touched will bring you to mind. Your laugh, your smile, your words will resound in my mind and heart. Goodbye, dear one.

— Helen Meier, Hope Hospice, Dublin, CA

Christian

Let not your hearts be troubled: believe in God, believe also in me. In my Father's house are many rooms; if it were not so, would I have told you that I go to prepare a place for you? I will come again and will take you to myself, that where I am you may be also.

— John 14: 1-3

Jewish

We rejoice over a birth and mourn over a death. But we should not. For when a man is born, who knows what he will do or how he will end? But when a man dies, we may rejoice — if left a good name and this world in peace.

— Jewish Midrash, Ecclesiastes Rabbah 7:1 (4)

Buddhist

Light without equal, so pure;
Beauty without peer, so serene;
We desire to be reborn with you.
Power without limits, so strong;
Glory without end, so majestic;
We desire to be reborn with you.

Muslim

Know, beloved, that we cannot understand the future world until we know what death is; and we cannot know what death is until we know what life is; nor can we understand what life is until we know what the spirit is — the seat of the knowledge of God.

— Al-Ghazali (1058-1111),
Muslim medieval mystic

Native American

As I walk,
The universe is walking with me
In beauty it walks before me
In beauty it walks behind me
In beauty it walks below me
In beauty it walks above me
Beauty is on every side
As I walk, I walk with beauty

— Traditional Navajo Prayer

Hindu

Never fear that old age will invade that city; never fear that this inner treasure of all reality will wither and decay. This knows no age when the body ages; this knows no dying when the body dies. This is the real city of Brahman; this is the Self, free from old age, from death and grief, hunger and thirst. In the Self all desires are fulfilled.

— Chandogya Upanishad