



Caregiver Guide

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An Instructional Guide for Caregivers

This is an instructional guide for the caregivers of Hospice patients at home. We hope that by giving you this information we can make you more knowledgeable of caring for your loved one.

Hospice works as an interdisciplinary group consisting of registered and licensed practical nurses, social workers, pastoral care, and hospice aide specialists, and volunteers joined together to help you care for your loved one. A registered nurse is on call 24 hours a day for your support when a new problem occurs or methods to alleviate a previously discussed problem are not successful.

Hospice is available to individuals who meet admission criteria. Referrals to Hospice can be made by family members, friends, clergy, and physicians. Most of Hospice costs are covered by Medicare, Medicaid, and major health insurance. No one is refused based on their ability to pay. We depend on outside contributions and donations to be able to offer this service to everyone. Many recipients of our service give donations in memory of their loved ones. This kind act enables us to continue our very special services to families and loved ones.

Avoiding Unnecessary Hospitalization

At Hospice of Orange & Sullivan Counties, we are committed to providing you with care and comfort in your own home. We are always available to guide you. Because of the nature of your illness, at times you may be tempted to seek more treatment, call 911 or an ambulance, or to go to the hospital – **however you must call your hospice team before doing so.**

Why is this so important? Most times we can successfully manage your care in your home and we will assess the situation fully before sending you to the hospital.

Insurance won't cover care from any provider that wasn't set up by the hospice medical team and you may be responsible for the entire cost. You must notify hospice and get approval **PRIOR** to going to the hospital. We never want you to receive surprise bills that can be avoided.

If you decide to seek additional care or further treatment, we may ask you to sign off of Hospice for this time period. We will help navigate what can be a complex system - finding support is easier than you think!

Situations where you may be tempted to go to the hospital include:

For dehydration and fluids

Most of the time IV fluids are not necessary and may actually be detrimental (please discuss this further with your nurse).

For pain, nausea, diarrhea or other symptoms

We have many options to manage your symptoms in your home. We will work with our specialized hospice physicians on a plan of care that meets your expectations and controls these symptoms in your home.

For active treatment

Including things like IV antibiotics, treatment of infections, chemotherapy, transfusions, etc. Active treatment likely will not be covered by insurance. We will help you manage decision-making and provide options. At times it becomes necessary to sign off of hospice for periods of time (this is called a revocation) while you seek additional treatment or aggressive care. This will allow you to seek additional care that would otherwise not be covered. In those instances, your regular insurance would take back over. We will help you through this procedure until you are ready to sign back on to hospice.

For fatigue/weakness

This is a normal concern and hospitalization rarely provides improvement.

When do I call hospice?

We encourage you call anytime that you need our support, advice and assistance. We are available 24 hours a day. You must call us before:

- Calling an ambulance
- Going to the hospital
- Having lab work
- Receiving radiation treatment
- Having an X-Ray, CT scan, MRI
- Doctor visits



Hospice Staff Safety and Household Pets

Our mission is to provide you with the highest quality of care. While you are on our program, you will receive visits from our interdisciplinary team, which may include RNs, LPNs, Hospice Aides, social workers, chaplains, and volunteers.

We are also committed to ensuring the safety of our staff during the provision of care. Household pets can present a danger to hospice staff by behaving in an unpredictable manner when faced with change and exposure to persons unknown to them. It is therefore our policy to require that patients and families secure all animals while Hospice staff is present in the home. Animals must be secured either by crating, or securing in another room of the dwelling, before and for the duration of the hospice visit.

We appreciate your cooperation to assist us in keeping our personnel safe and allowing us to provide you with excellent care without distractions.

Medications are an important part of your hospice care. Some medications are necessary, to help aid in comfort, but some medications may no longer be necessary and may be harmful.

Necessary Medications



- **Narcotics** (oxycodone, fentanyl patches, dilaudid, morphine, etc): These help to control pain and shortness of breath.
- **Anti-anxiety medications** (Ativan, Xanax): These help to control anxiety, nervousness, and sometimes shortness of breath at the end of life.
- **Anti-nausea medications** (zofran, compazine, reglan, etc).
- **Anti-agitation medications** (haldol, thorazine, etc)- these medications are very good for restlessness and agitation that are sometimes seen at the end of life.
- **Anti-constipation medications** (colace, senna, miralax, suppositories, etc).
- **Anti-secretion medications** (glycopyrrolate, scopolamine patch, atropine drops)- help limit secretions that we sometimes see at the end of life.

Potentially Unnecessary Medications



- **Anti-diabetic medications:** (Insulin, metformin, glipizide, etc). Unless you are a type 1 diabetic prone to DKA or diabetic coma (HHNK), the risks of taking insulin (hypoglycemia) are often greater than the benefits. As the appetite slows down, taking insulin might be very risky. Tight control of sugars is usually unnecessary, and a general goal should be to keep sugars less than 360g/dL.
- **Anti-hypertensives** (metoprolol, carvedilol, lisinopril, HCTZ) ; It is sometimes risky to try and keep the blood pressure low towards the end of life (dizziness, passing out, falls, etc).
- **Aspirin**
- **Blood thinners** (coumadin, lovenox, eliquis, etc)- these are very risky medications (risk of severe bleeding).

Unnecessary Medications



- **Statins** (Lipitor, Crestor, etc).
- **Herbal medications, vitamins, over the counter medications and supplements.** (vitamin D, daily multivitamins, iron, fish oil, etc).

Pain Management

“Pain is what your loved one says it is”. Your loved one may experience pain as discomfort, aching, restlessness, anxiety, or cramping. A main objective of Hospice is to keep your loved one at their acceptable level of comfort. Here are a few guidelines to follow:

- Give pain medications at the prescribed times. This maintains a level of pain medication and keeps your loved one comfortable.
- When a person is alert, they can tell you when they are in pain.
- When a loved one is unresponsive or in a coma-like state, they will not be able to communicate what they are feeling. Look for signs of restlessness, moaning or wincing. These are some non-verbal signs of pain.
- Continue to give medication as prescribed and change your loved one’s position for comfort.
- Your loved one should be as comfortable as possible. If for any reason the pain medication is not working, call the Hospice nurse.
- A plan of action will be taken either to increase the pain medication or change it.
- Some medications are given as a suppository. The Hospice nurse can show you how to administer a dose.
- If you are giving pain medication by mouth and your loved one is having difficulty swallowing the pill, call the Hospice nurse.
- Pain medication can be prescribed in a different form or prepared in a different manner.

Dear Hospice Patient

- Your hospice team is concerned about your pain.
- There is no benefit to suffering with pain.
- Pain can usually be well controlled with medicines that are taken by mouth.
- If these medicines do not work, many other options are available.
- Morphine or morphine-like medicines are often used to relieve pain.
- The team will teach you how to use methods to enhance the medicine such as deep breathing, guided imagery, relaxation, prayer, etc.
- If these medicines are used now, they will still work later.
- Communication with your nurse and the team about pain is critical.
- The nurse will ask about any problems the pain medicine might be causing, since there are ways to make the problems better.
- The nurse wants to know if there are any problems getting the medicine or if you have any concerns about taking medicine.

Hospice is asking for your help in treating your pain.

As part of each visit, we will ask you to describe your pain as best you can. Does it hurt to touch the area? What makes it better, what makes it worse- for example, a change in position, a certain activity or when taking a deep breath? Pain can be expressed as:

aching pressure burning sharp stabbing pain
nagging cutting tingling pressing squeezing
itching pricking crushing pulsing cramping
boring gnawing stinging shooting dull ache

The hospice nurse will also ask you to rate your pain using a pain scale. This is very important because it tells us how well your medication is working or if an adjustment is needed. We use the pain scale like the ones pictured on the back of this page.

Pain management is treating pain before it interferes with your life.

0 no pain _____ **10** the worst you can imagine

1-3 would be some aching but not interfering with your life

4-6 on the scale would be moderate pain, that starts to prevent you from doing activities

7 or more is severe pain

Hospice will ask you what your pain is now and what it is like at its worst.

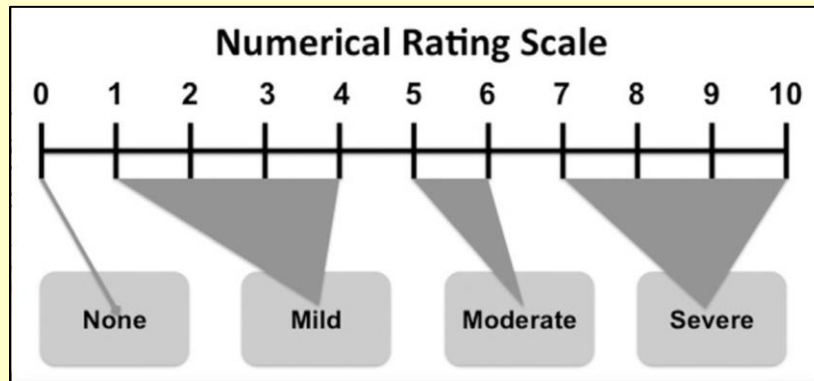
Hospice will also ask you what your comfort goal rating is. A person's goal rating is individual. It is the amount of pain that you are willing to tolerate. Your goal might be around a 3-4. The personal goal should not prevent you from doing activities or interfere with sleep. Your comfort goal is also a tool to assist the nurse to better understand your treatment options.

Hospice will believe your report of pain and will work with you to reach your goal as best we can.

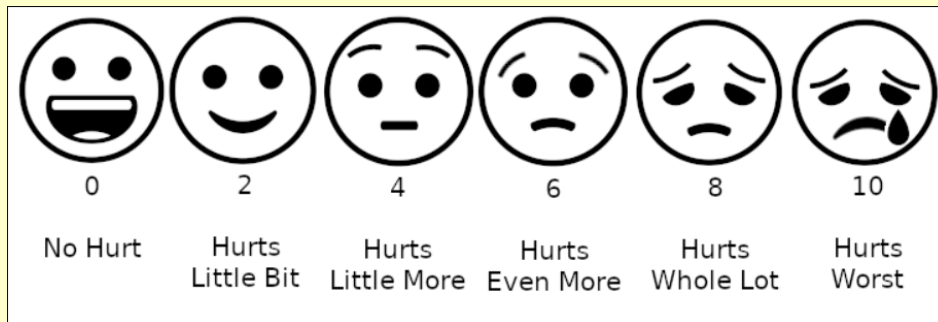
Hospice is committed to helping you remain as comfortable as possible.

Pain Scales

Numerical Scale



Wong-Baker Faces Pain Rating Scale



Non-Verbal Scales

Sometimes patients cannot verbalize their pain. The nurse will observe for non-verbal pain indicators and help family members/caregivers learn these tools as well.

FLACC Scale (Face, Legs, Activity, Cry, Consolability)

Categories	0	1	2
Face	No particular expression or smile.	Occasional grimace or frown, withdrawn, disinterested	Frequent to constant frown, quivering chin, clenched jaw
Legs	Normal position or relaxed	Uneasy, restless, tense	Kicking or legs drawn up
Activity	Lying quietly, normal position, moves easily	Squirming, shifting back and forth, tense	Arched, rigid, or jerking
Cry	No cry (awake or asleep)	Moans or whimpers; occasional complaint	Crying steadily, screams or sobs, frequent complaints
Consolability	Content, relaxed	Reassured by occasional touching, hugging, or being talked to; distractable	Difficult to console or comfort

Breathing Care

- Keep your loved one's room cool and well ventilated.
- Allow your loved one to rest between meals and after a bath.
- Place a small oscillating fan at your loved one's bedside to help them feel as if they are receiving more air.
- If the mucous is thick, offer (warm) fluids and use a room humidifier.
- Remove all highly scented items from their living area.
- Eliminate smoking from their immediate area.

If your loved one is having trouble breathing and is short of breath, signs include restlessness, rapid, short, shallow breaths, and anxiety. This can be very frightening for both of you but there are some things you can do.

- If your loved one is in bed, raise the head of the bed or have them sit up. Put pillows behind them and make sure they are well supported. You can ask them to lean forward and encircle their arms around a pillow or over an over-the-bed table. Place them in the position they identify as most comfortable.
- Stay calm and reassure the patient.
- At this time, keep supportive family and friends at a minimum. One to one support is best. Take turns if necessary.
- If oxygen is in home, administer it until shortness of breath subsides.
- If all interventions are unsuccessful, contact hospice nurse.
- Have the patient do deep breathing exercises. This will help them to get more oxygen and calm their breathing. The steps are as follows:
 - Breathe in and out slowly through the nose, using the stomach muscles. Feel the abdomen rise and fall with each inhalation and exhalation.

Pursed-Lip Breathing

Breathe in slowly through the nose. Hold your breath and count to three. Purse the lips as if to whistle. Breathe out slowly through pursed lips, to the count of six.

Oxygen Therapy

There may come a time when oxygen is needed. The doctor will decide on the best time and the appropriate amount. The company that supplies the equipment and your Hospice nurse will give you training on how to use it when it is delivered to your home. You can call your Hospice nurse if you are having any problems with the oxygen. Here are some things to remember:

- Keep the masks or cannula clean, using a wet cloth to wipe it.
- Check the nose, ears and check for reddened areas caused by the elastic and tubing. Use soft cotton pads between tubing/elastic and the skin.
- Oxygen can dry out the mucous membranes in the nose, so you may want to check the nostrils and mouth for dryness. You can put water-soluble jelly such as K-Y Jelly on the lips and nostrils to help keep them moist. Do not use petroleum products.
- If you cannot tell if the oxygen is flowing, check the tubing for kinks, blockages or disconnection. Make sure the oxygen has been turned on. You can put the prongs of a nasal cannula in a glass of water. If you see bubbles, the oxygen is flowing.
- Remember to position the prongs of the nasal cannula in the nostrils, facing upward and following the curve of the nostrils.

Oxygen Safety

- Keep all oxygen equipment at least 10 feet from any type of open flames.
- Oxygen must be used at the prescribed liter flow and not changed without an order from a physician.
- Smoke detectors should be in use whenever and wherever oxygen is used. Fire extinguishers should be present in home.
- Oxy-concentrator is placed close to patient area in open space, minimum 1 foot clearance.
- NO SMOKING!!! It is the recommendation of Hospice of Orange & Sullivan Counties, Inc. that this includes e-cigarettes.
- Removal of Flammables (aerosols, lotions, petroleum products, electric razor, blow dryer, electric blanket, etc.) while Oxygen is in use.
- Aerosols should not be sprayed in a room with an oxygen source.
- Oxygen will not burn or explode. However, it will make a fire burn very hot and faster than normal.
- Rescue cylinders should never stand upright alone. Tanks should be stored in carts or lay flat on the floor in ventilated area free from heat or sunlight.
- Connect only the concentrator to a single sturdy grounded electrical wall outlet. A loose connection may cause overheating and increase the risk of fire.
- Never use an extension cord except the one approved by the Oxygen supply company.

Safety Tips

- Do not smoke or allow others to smoke in the same room as the oxygen. Signs should be posted on doors.
- Do not use the oxygen or keep the equipment near open flames or heat sources such as stoves or radiators.
- Make sure a fire extinguisher is handy.
- Make sure you can see the tubing at all times. Don't hide it under blankets or rugs.
- Turn the oxygen off whenever it is not being used.
- Store unused oxygen cylinders flat.

Proper Storage for Oxygen Tanks:

Tanks must be lying flat on the ground or in a designated oxygen tank holding cart or stand.



Improper Storage of Oxygen tanks:

DO NOT store tanks in an upright position without being secured in a designated cart or stand.



Activities of Daily Care:

Basic Hygiene

If your loved one is unable to wash themselves, there are some easy steps to follow.

- Gather wash basin, towel, and wash cloth or sponge. Frequently change water. Water should be warm rather than hot. Use mild soap. Wash, rinse and completely dry separate areas. Wash the face and neck first. Then bathe the trunk and arms, legs and feet and lastly perineal areas. Always dry each area completely.
- Look for any reddened areas, especially the bony parts, or pressure areas (elbows, heels, upper buttocks, shoulders, even ears). You can apply lotion to reddened areas.
- Include mouth care. If your loved one is unable to brush their teeth you should provide mouth care at least twice a day. Gently brush natural teeth or remove dentures and clean them.
- If your loved one is unresponsive, a mouth toothette should be used. Either a toothette or a 4"x4" gauze pad squeezed almost dry with water can be used to clean and refresh the mouth, (the nurse will supply you with toothettes, if needed). Remember, an unresponsive patient may not be able to swallow, so use only a small amount of liquid.

Care of the Skin

Keeping the skin in good condition is very important, especially if your loved one is bed-bound or is not able to change their position very often. A good time to check the skin is during the bath.

- Dry skin may look flaky and white, may itch or be red and look like a rash. Ask your nurse to check any changes you notice, especially if you see redness over any of the pressure areas. This may be the beginning of a pressure sore. Although it is up to your nurse and doctor to decide what treatment will help the area heal, there are several things you can do to lessen the risk of developing pressure sores.
- Encourage your loved one to change position frequently in bed or shift from side to side in a wheelchair.
- Apply lotion gently to the bony areas. Make sure pain medication is given to your loved one who has pain. This will make them more willing to move and easier to do so.
- Items such as special mattresses, elbow and heel protectors may be necessary to further protect the skin.
- Keep their skin clean and dry.
- Keep the sheets dry and smooth out any wrinkles.

Lifting and Positioning

Try to remember the #1 rule, always lift with your legs and not your back. Take an extra moment to think about lifting before you do it. It is important to learn how to lift with the least strain on yourself.

Getting Someone Out of the Bed

If you have difficulty in performing this procedure, do not hesitate to ask your nurse to demonstrate for you.

- Roll your loved one on their side, facing you. If you have a hospital bed, raise the bed. If not, place your arms under the patient's underarm and gently pull to a sitting position. Bring the legs around to dangle from the bed.
- If your loved one cannot sit up alone, put one arm around the back of the shoulders, supporting the neck, and with the other arm gently pull forward to the edge of the bed. Reposition yourself to insure positive balance. Put both arms around the patient under the arms. Have your loved one put their arms around your neck.
- Brace your knee against the patient's knee by placing one leg between the patient's legs and gently lift up.
- When both of you are standing, turn towards a chair and gently let the patient sit. Remember to have the chair in a nearby position to make moving easier.
- Also, if lifting to a wheelchair be sure it is in a locked position.

Getting On and Off the Bedpan

If your loved one is not able to get out of bed or if it is easier to use a bedpan at night, use the following steps:

- Wear protective gloves.
- When your loved one is on their back, you can begin by crossing their legs.
- If you are rolling your loved one to turn to the left, place the right leg over the left, and cross the right arm over the chest. Your loved one may be able to grab the side rail to help you.
- When their leg and arm is crossed over, place your hands under their back and roll your loved one on their side.
- Place the bedpan as close as possible to your loved one's buttocks and then you can roll your loved one on to the pan while stabilizing the pan.
- Fracture pan – place the handle to the front and the flat part against your loved one's back.
- When your loved one is finished, follow first three steps to remove the pan.
- When the pan is removed, keep your loved one on their side to wash and dry the area. It is easier to clean the perineum while your loved one is still on their side. Then you can roll your loved one on their back.
- Remove protective gloves and wash your hands.

Positioning a Loved one in Bed

You can use the same technique as positioning your loved one on their side.

- Use pillows to place behind your loved one's back to prevent them from rolling.
- You can also use small pillows or soft, thin blankets to place between the legs and arms to prevent pressure.
- Remember, it is very important to change your loved one's position often.
- After positioning, always look and see if your loved one is comfortable.
- Think of yourself and if you would be comfortable in that position.
- Ask if they are comfortable.

Use of a Draw Sheet

If your loved one is unable to move, you can use the help of a draw sheet. This can be a soft blanket or folded sheet, large enough to reach from shoulders to med-thigh, with six inches or more on either side for you to hold it.

- Place the sheet under your loved one using the same technique of rolling your loved one on their side (see bedpan placement).
- Keep the draw sheet wrinkle free under your loved one to prevent pressure sores.
- When the draw sheet is under your loved one, you can then lift your loved one higher in the bed or roll from side to side using the draw sheet.
- Use two; one person on each side of the draw sheet.
- Roll the draw sheet in toward your loved one on either side. On the count of three, move your loved one in unison.

Rehabilitation Techniques

Upon admission to Hospice, and ongoing, the RN will assess your loved one for functional limitations that need to be addressed to help your loved one reach maximum independence. Based on the assessment, the RN will provide information and instructions regarding rehabilitation techniques.

Fall Reduction Program

The Hospice nurse will review fall prevention interventions specific to your loved one's risk for falls.

For all patients, maintain safe environment:

- Remove excess equipment/supplies/ furniture from rooms and hallways
- Coil and secure excess electrical and telephone wires
- Encourage prompt cleaning of all spills immediately
- Orient patient to surroundings, including bathroom location
- Keep bed in lowest position during use
- Keep 2 (two) top side rails up for spatial awareness or bed mobility if applicable

- Secure locks on beds and wheelchairs
- Recommend use of tap bell and leave within patient reach and answer promptly
- Place frequently needed objects within reach
- Encourage use of adequate lighting, especially at night
- Encourage use of properly fitting nonskid footwear
- Encourage use of assistive devices (i.e.: walkers, cane, etc.)
- Encourage patients/families to call for assistance

For those patients with moderate risk for falls:

- Monitor and assist patients in following daily schedules
- Supervise and/or assist bedside sitting/personal hygiene, and toileting as appropriate
- Reorient confused patients
- Establish elimination schedule, including use of bedside commode, if appropriate
- Evaluate need for slip resistant chair mat (do not use shower chair)
- Evaluate need for use of a self-releasing seat belt when in wheelchair if appropriate
- Encourage use of pediatric monitor
- Reassess use of DME (Durable Medical Equipment)

For those patients at a high risk for falls:

- Remain with patient while toileting
- Encourage frequent supervision by family members
- Move patient to area with best visualization of patient
- Encourage family to remain with patient during the night
- Encourage family participation in patient care
- Encourage use of a medical alert device

Nutrition

An adequate and nutritious diet can make a difference in having enough energy and strength to do some of the activities that are important to your loved one and allow them to maintain as much independence as possible. Sometimes, though, your loved one may lose their appetite.

Tips for better nutrition

- Make breakfast the biggest meal. Appetite may decrease as the day goes on.
- Prepare small, frequent meals throughout the day.
- Supplement meals with nutritional drinks or puddings like Ensure, Carnation Instant Breakfast, Boost, and Glucerna (for diabetics).
- Do not fill your loved one up by providing a lot of liquids during meals.
- If your loved one has a loss of appetite, you may want to try the following ideas: Freshen your loved one's mouth before eating. Food will taste better. Brush their teeth or rinse with water. Wash their hands and face and make them comfortable in bed or at a table.
- Eat meals together and keep the atmosphere relaxed, comfortable and well lit.
- Offer a variety of foods.
- Add sauces and gravies to dry food.
- Make sure pain medication is given on time so your loved one is not in pain either before or during meals.
- If nausea and vomiting are a problem, here are some things you might try. Give anti-nausea and/or appetite stimulating medication as prescribed, not skipping a dose if they start to feel better.
- Avoid foods with strong odors, like onions. Offer mild or "no-odor" foods like applesauce, mashed potatoes, rice with butter, baked potato with sour cream, or yogurt. Cooking odors may also bother your loved one. Ask others to cook at their house and bring the food to you.
- Avoid fatty foods like fried chicken or french fries.
- Avoid very sweet or spicy foods.
- Try to offer dryer foods like toast or crackers.
- Try Lactose free milk if your loved one has problems with milk intolerance.
- Yogurt may be helpful to maintain GI functioning.
- To add more calories to the diet you can: mix nonfat dry milk with regular milk. It is best if refrigerated overnight. Make milk shakes with ice cream and nutritional drinks. Add milk instead of water to gravies and soup. Keep dried fruits, peanut butter, nuts, and cheese on hand for snacks. Keep in plastic bags. Use butter or margarine on starchy foods like potatoes and rice.

- Above all else, do not force your loved one to eat. Remember that mealtimes can be a perfect time for closeness and sharing, so make them enjoyable for both of you.
- If your loved one cannot get up to a chair for meals, you will have to feed them in bed. Here are some ideas to follow:
- Assist your loved one to use the bathroom, bedpan, urinal, or commode and wash their hands. Wash your hands also.
- Raise the head of the bed or use pillows to prop your loved one into a sitting position.
- Use over the bed table or a bed tray for a flat surface. One that has raised sides and fits over the lap is best and reduces accidents. Use cups with covers and straws to reduce spills.
- Use a spoon instead of a fork for better control and less chance of injury to the mouth.
- Cut the food into bite-size pieces and serve at room temperature.
- Allow them to feed themselves if possible so they will not feel so helpless. If they cannot see well, help them locate the food on their plate according to the position of clock hands.
- Do not rush them through the meal. Make this a time for pleasant conversation.
- Fluids, specifically water, (even though water does not provide any vitamins or calories) are important. They are needed to keep the skin and mucous membranes moist, and to carry nutrients to all the cells in the body and waste products away from them.
- Here are some things to keep in mind regarding your loved one's intake of fluid.
- **Do not force** them to drink. Rather, offer a choice of beverages.
- Try to have them drink as much water each day as possible, (if water is not difficult to swallow). Keep in a thermal cup. Cold water is refreshing.
- Offer juices and nutritional supplements. They also help with regulating bowel movements. Jell-O, puddings, ice cream and broth are also liquids you can offer.
- Use small juice boxes, squeezing gently to push fluids up and out of straw.
- Use a straw, sippy cup or even a spoon if your loved one cannot use a cup. If your loved one cannot suck hard enough on a straw to draw up liquid, try cutting the straw in half.
- Flavored ice cubes (made from fruit juice) crushed into ice chips can be enjoyable.

Elimination

When a person becomes very ill, they may have problems with controlling their urine and stool. This can be very upsetting and embarrassing to your loved one and caregiver. You, the caregiver, must be very kind and understanding and maintain your loved one's dignity. Another problem that may occur is lack of (decreased output) urine or stool.

Urine and Stool Incontinence

- Place a chux or absorbent paper under your loved one.
- Change your loved one when they are soiled with either urine or stool, wearing protective gloves.
- Wash the area with warm soapy water, rinse and completely dry.
- Apply lotion to reddened areas.
- Use the technique of rolling your loved one from side to side to change the chux, absorbent paper or diapers.

Small amount of urine

If your loved one has not urinated in 12 hours and/or the stomach appears bloated or enlarged, call the Hospice nurse. This may be due to small amounts of liquids taken by your loved one, or inability to urinate on their own.

Foley Care

Many patients come home with a foley catheter. This is a small, flexible rubber-like tube anchored with a balloon inserted into the bladder, which allows urine to flow through to a large collection bag. This enables your loved one to remain dry.

- Put on protective gloves; wash the area where the tube enters the body with warm, soapy water; washing and rinsing away from the body.
- Rinse well and completely dry. This should be done at least once a day.
- Make sure tubing from patient to collection bag is without kinks, or folds.
- Always place collection bag below the patient. This is so gravity will draw urine into the bag.
- Sometimes a foley catheter will leak. If that happens, place a chux or absorbent pad under your loved one. Call the Hospice nurse and she will evaluate the problem.
- Empty collection bag twice a day into a collection container and dispose of urine in toilet. There is a special spout at the bottom of the bag. Remove protective gloves and wash hands.
- The nurse or home health aide will demonstrate how this is done.

Constipation

Hospice patients often experience constipation due to decreased physical activity, changes in diet, some treatments, or medications. Here are some suggestions that may help.

- Increase your loved one's activity if possible.
- Increase fluids and fiber in your loved one's diet, if tolerated, such as water, juices, fruits, bran, and vegetables.
- Provide stool softeners and laxatives as instructed.

Diarrhea

Poor digestion and absorption along with certain treatments and medications may cause your loved one to experience diarrhea. Here are some guidelines to follow.

- Review your loved one's dietary intake for the past 24 hours.
- Increase fluid intake.
- Encourage your loved one to eat small amounts frequently.
- Provide foods that are mild and tend not to cause diarrhea, e.g., rice, bananas, applesauce (no skins) or toast.

Disposal of Medical Waste

This section provides education about how to safely dispose of needles and other contaminated medical waste, such as soiled disposable sheets (chux) and bandages.

You can help prevent injury, illness, and pollution by following some simple steps when you dispose of the sharp objects and contaminated materials you use in administering care in your home. You should place: **Needles, Syringes and other sharp objects** in a hard-plastic or metal container with a screw on or tightly secured lid. Keep container in an upright position. Fill no more than two thirds full. A Sharps Container can be provided by your Hospice staff.

Do not put sharp objects in any container that will be recycled or returned to a store. Do not use glass or clear plastic containers. Finally, make sure that you keep containers with sharp objects out of reach of young children.

Medication disposal will be discussed with you in more detail by your Hospice nurse.

We also recommend that **soiled bandages, disposable sheets, and medical gloves** be placed in securely fastened plastic bags before you put them in the garbage can with your other trash.

Hospice of Orange and Sullivan Counties, Inc.

Policy on Management and Disposal of Medications including Controlled Substances

POLICY'S PURPOSE

The following are instructions for patients and families/caregivers regarding the safe and effective use, storage, and disposal of medications including controlled substances.

Your Hospice nurse will review this information with you on admission and periodically during the care of your loved one.

At any time, you may report any concerns about safe/effective use of medications to Hospice staff.

PROCEDURE

Safe Storage

Medications should be:

- Stored separately from other poisonous drugs and chemicals
- Removed from storage during instruction and administration times
- Kept out of the reach of children, pets, and confused or disoriented patients
- Stored inside the refrigerator if refrigeration is required

Oral medications should be stored separately from topical medications.

If it is a multi-use vial, the medication should be discarded 28 days after the date it is opened (label will be provided by hospice nurse) or sooner if solution is compromised.

Controlled substances will be distributed directly to the patient or their representative by the dispensing pharmacist

Disposal of Controlled Substances

The Hospice nurse will facilitate the disposal of controlled substances.

They will use a deactivation system pouch to ensure proper disposal:

- The medication will be removed from the original container and poured into the Deterra Drug Deactivation System pouch.
- The container/pouch will be filled halfway with warm water.
- Wait 30 seconds and seal tightly. Gently shake.
- The pouch will be disposed in the garbage receptacle

Caregivers/families can refuse to allow the nurse to dispose but this is not recommended. If this is desired, the medication should be kept in a locked cabinet away from the reach of children until such time as the family/caregiver disposes of the medication. The disposal or declination of disposal will be documented in the clinical record.

Disposal of All Other Medications

Per the New York State Department of Environmental Conservation (NYS DEC), the following guidelines are to ensure medications are disposed of safely, preventing accidental or intentional ingestion and contamination of our waterways.

1. Preferred methods:
 - Find a collection site near you. A link is on the NYS DEC webpage, Safe Medication Disposal for Households: dec.ny.gov/chemical/67720.html
 - Take advantage of the National Drug Take-Back Day
 - Contact your local pharmacist to see if they are aware of other medication disposal programs in the area

2. If no take back program is available, take the following steps to dispose of the medications in the trash:
 - Mix medications (do not crush tablets or capsules) with water and then add salt, ashes, dirt, cat litter, coffee grounds, or another undesirable substance to avoid accidental or intentional misuse of drugs.
 - Do not conceal discarded drugs in food.
 - Place all medications in an outer container, such as sealable bag, box, or plastic tub to prevent discovery and removal from the trash. Seal the container with strong tape.
 - Dispose of drugs as close to your trash collection day as possible to avoid misuse and/or misdirection.

Disposal of Sharps Containers for the Community

BON SECOURS COMMUNITY HOSPITAL

Monday through Friday
Bring to Information Desk in the Main Lobby
845-858-7000

THE CARE CENTER AT SUNSET LAKE

Daily
Facility entrance
845-292-8640

GARNET MEDICAL CENTER

Drop off through Emergency Room Entrance to Security Command Center
Bring to the Security Office located in the Emergency Room and fill out small form
Place in a Heavy/Thick plastic detergent bottle-TAPED
845-333-1000 Security

ROCK HILL HEALTHMART PHARMACY

Bring to the Counseling Room of the Pharmacy
845-791-1515

MONTEFIORE ST. LUKE'S CORNWALL HOSPITAL- CORNWALL CAMPUS

Mondays
Bring to the front desk in the main lobby
Should be in a sharps container or a thick plastic container with screw-on lid and labeled with name and address with "biohazard" written on the container
845-534-7711

MONTEFIORE ST. LUKE'S CORNWALL HOSPITAL- ST. LUKE'S CAMPUS

Wednesdays
Bring to the front desk in the main lobby
Should be in a sharps container or a thick plastic container with screw-on lid and labeled with name and address with "biohazard" written on the container
845-561-4400

For more results, use <https://safeneedledisposal.org/state-search/>

Emotional Care

Emotional care is every bit as important as the relief of pain. Many people feel anger or depression at the thought of dying; feelings of guilt or regret over the past are also common. Loving and caring support from family, friends and Hospice staff, will assist your loved one with their end-of-life journey.

A great cause of anxiety and worry may be fear of a painful end. Loved ones should be reassured that adequate pain relief will be always maintained, and that even when death is near, they need not fear suffering. Most people drift into unconsciousness just before the end and die “in their sleep”.

Fear of dependency and loss of dignity may also cause worry. The dying person should be allowed to participate as much as possible in family discussions and decisions.

Preparing for death may include practical matters such as writing a will or planning funeral arrangements. It may include less tangible things such as saying “I’m sorry”, “thank you” or “goodbye”. Confession or reassurance from a member of the clergy or a pastoral care minister is also important for some people. Perhaps the most pressing need for the terminally ill person is open, honest communication. Relatives, friends, and caregivers must be willing to share the dying person’s concerns.

Emotional Needs

Care of the terminally ill is not limited to physical needs. The dying person has specific emotional needs that must be met. Family, friends, and caregivers should be sensitive to the following needs.

- The need for open, honest communication
- The need for emotional stability
- The need to talk and share feelings
- The need to be included
- The need for someone to listen
- The need for understanding
- The need for unconditional love
- The need for your time and patience
- The need for intimacy through human touch
- The need for reassurance
- The need for laughter and pleasure.

Taking Care of Yourself

Taking care of your loved one at home can be very rewarding. It can also physically and emotionally drain you and your family members. You may feel that you have no time for yourself and that your responsibilities are overwhelming. Emotionally, you may be trying to deal with the impending loss of a loved one, trying to be involved with your family, and you may have no one to talk to about your own feelings. Physically, you are caring for the needs of your loved one, your home and your family. But, while you are doing all these things, you may be neglecting a very valuable person.... yourself. If you do not take care of yourself, you will not be able to care for your loved one.

Some of the things you can do to meet your own needs are:

- Get enough rest. You will find your outlook and ability to deal with things are greatly improved. Try to get at least six hours of sleep a night and take naps during the day while the loved one is sleeping. If you are “all wound up” try doing some deep breathing exercises, listening to music you find relaxing or taking a warm bath or shower. If you are having trouble falling asleep, try some warm milk, or read for a while.
- Eat well. If your meals are well balanced and you do not skip meals, your resistance to disease will be better and you will have more energy. Do not try to diet during this time. Try to watch your caffeine intake also.
- Delegate. Do not try to do it all yourself. Ask family members to share in the care of your loved one. Ask family, friends, or neighbors to take over for you so you can go out for a few hours. Ask your church or synagogue if there are members willing to help with things like meals, shopping, cleaning, or respite.
- Request a Hospice volunteer.
- Talk to someone. Find a person you can confide in, or talk to your Hospice social worker, nurse, spiritual care, volunteer, or clergy. You will be surprised by the good response.
- Take time for yourself. Schedule time off for yourself to do things you have always enjoyed doing. If you have had to take a leave from your job, arrange to have lunch with a coworker. You can ask them over if you cannot leave the house and they can bring something. Make a list of the loved one’s friends and invite them for “tea” or lunch. Remember that taking time for you is not selfish. Do not be afraid to laugh. You will find that laughing has healing powers.

The Experience of Death

At some point, the active part of the dying process will begin. This process is not the same for everyone, but there are certain things you can expect. You may feel that you are fully prepared for the death of your loved one until this process actually begins. To help you through this transition and to assist you in supporting your loved one, there are some things you can recognize as death approaches. We encourage you to speak with your Hospice team.

Some Physical Signs of Death

- The ability to move and feel sensation is lost, beginning in the legs and then the arms. Pressure from tight fitting sheets can irritate your loved one. Keep bedclothes loose and help them change position often.
- Your loved one may start to perspire heavily, especially on the upper part of their body, and their temperature may rise.
- They may be too hot and seem restless. Provide a well-ventilated atmosphere and keep the bedclothes light.
- You may find that although their temperature is higher, their body will feel cool to the touch.
- Their skin color may be mottled and have a bluish color, especially in the feet and legs.
- Sight and hearing may begin to fail. Sit near your loved one's head and talk to them directly. Do not assume your loved one cannot hear you.
- Your loved one may sleep more and communicate less. Continue to talk to, sit near and touch your loved one. Touch is very comforting.
- Do not whisper to others within hearing of your loved one. They may think you are trying to hide something from them.
- Your loved one may be confused and think they are living in a past time of their life. They may think they are younger and that you or others are someone else. Try not to get upset if they do not recognize you at times.
- Keep talking to them and reorienting them to time and place.
- Bowel and bladder control may be lost.
- Your loved one may sound very congested, like they must clear their throat. The amount of oral secretions may increase.
- It may help to turn their head to the side, raise the head of the bed a little, place a towel under their head to catch the secretions and gently wipe out their mouth with a damp cloth.
- You may see meaningless, repetitive movements increase. Do not restrain your loved one and avoid loud, sharp, and sudden noise. Playing music is more soothing.
- Desire for food or fluid may decrease or stop altogether. Offer ice chips or sips of juice and refresh their mouth frequently. Do not try to force them to eat or drink.

- Urine output may decrease. If your loved one does not have a catheter, your nurse may want to suggest diapers or a catheter, if necessary.
- Your loved one may begin to have 10-20 second periods of no breathing, called apnea; followed by short, shallow, and rapid breathing. Keep the head of the bed raised and hold your loved one's hand, talking gently.
- If you feel that death is near, you may want to have family and friends come to say goodbye to the patient and express their love for the patient.
- **Call the Hospice Nurse** at this time to tell her/him that changes have occurred.
- You will know death has occurred when there has been no breathing or heartbeat for several minutes. You do not need to do anything immediately. Their eyes will look fixed at one spot and no blinking will occur. Their mouth may be partly opened and your loved one will be motionless.
- **After death has occurred, call Hospice at 1-800-924-0157. Do not call 911.** Tell the person who answers that there has been a death, tell them the loved one's name, your name, and your phone number. They will have a Hospice nurse call you, they will come to your home, confirm that death has occurred, and assist you with the details. They can call the funeral home of your choice and will also notify the doctor.
- Hospice care does not stop here. Hospice of Orange and Sullivan Counties continues to keep a supportive relationship with you and your family for as long as thirteen months after the death of your loved one.
- Counseling and bereavement support groups are available for you if you desire.
- Visit us on the web at <http://www.hospiceoforange.com> Hospice of Orange and Sullivan Counties is on call 24 hours a day. If you need help or are having a problem, call **845-561-6111 or 1-800-924-0157.**

To prevent health care errors, patients are urged to...

Speakuptm

Everyone has a role in making health care safe.

That includes doctors, health care executives, nurses, and many health care technicians.

Health care organizations all across the country are working to make your care safer by encouraging you to become an active, involved and informed member of your health care team.

This program gives simple advice on how you can help make health care a good experience. Research shows that patients who take part in decisions about their own health care are more likely to get better faster. To help prevent health care mistakes, patients are urged to “Speak Up.”

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

- Your health is very important. Do not worry about being embarrassed if you don't understand something that your doctor, nurse or other health care professional tells you.

Pay attention to the care you get.

- Tell your nurse or doctor if something doesn't seem right.
- Expect health care workers to introduce themselves. Look for their identification (ID) badges.
- Notice whether your caregivers have washed their hands. Hand washing is the most important way prevent infections. Don't be afraid to remind a doctor or nurse to do this.
- Make sure your nurse or doctor checks your ID. Make sure he or she asks your name and date of birth before he or she gives you your medicine or treatment.

Educate yourself about your illness.

- Write down important facts your doctor tells you. Ask your doctor if he or she has any written information you can keep.
- Read all medical forms and make sure you understand them before you sign anything. If you don't understand, ask your doctor or nurse to explain them.
- Make sure you know how to work any equipment that is being used in your care. If you use oxygen at home, do not smoke or let anyone smoke near you.

Ask a trusted family member or friend to be your advocate (advisor or supporter).

- Your advocate can ask questions that you may not think about when you are stressed.
- Ask this person to stay with you, even overnight, when you are hospitalized. You will be able to rest better. Your advocate can help make sure you get the right medicines and treatments.
- Your advocate can also help remember answers to questions you have asked. He or she can speak up for you when you cannot speak up for yourself.
- Make sure this person understands the kind of care you want and knows who you have appointed as your healthcare proxy. Make sure he or she knows what you want done about life support and other life-saving efforts if you are unconscious and not likely to get better.
- Go over the consents for treatments with your advocate before you sign them. Make sure you both understand exactly what you are about to agree to.

Know what medicines you take and why you take them. Medicine errors are the most common health care mistakes.

- Ask about why you should take the medication. Ask for written information about it, including its brand and generic names. Also ask about the side effects of all medicines.

Update your health care team regarding any changes that could affect your safety.

- This could include changes in your vision or balance.
- This could also include environmental changes such as malfunctioning equipment.

Participate in all decisions about your treatment.

- You and your doctor should agree on exactly what will be done during each step of your care.
- Know who will be taking care of you. Know how long the treatment will last. Know how you should feel.
- Remember, you are the center of the health care team.

The SpeakUp™ program is sponsored by The Joint Commission. They agree that patients should be involved in their own health care. These efforts to increase patient awareness and involvement are also supported by the Centers for Medicare & Medicaid Services.

Complaints / Grievance Policy

- To voice concerns, complaints or grievances regarding care or services the patient is receiving by anyone who is furnishing services on behalf of the hospice without fear of restraint, interference, coercion, discrimination, or reprisal. Hospice of Orange & Sullivan Counties, Inc. strongly urges patients and/or families to call any team member and/or a supervisor with any and all questions, concerns or complaints about your care and service. Hospice of Orange & Sullivan Counties, Inc. will respond and immediately investigate the complaint. The Administration at Hospice of Orange & Sullivan Counties, Inc. can also be called (800) 924-0157. If you feel that the response is not satisfactory, an appeal may be requested. Appeals are reviewed and addressed within 30 days of a request.
- At any time, the patient has the right to call the New York State Department of Health at (800) 628-5972. You may also call The Joint Commission (800) 994-6610 or email: complaint@jointcommission.org, or any other person/agency of your choice and remain free from restraint, interference, coercion, discrimination, or reprisal.

Community Resources

Orange County

Offices and Departments:

Aging	845-615-3700
Health	845-291-2332
Community Health Outreach	Middletown: 845-341-0101 Newburgh & Goshen: 845-568-5237 Port Jervis: 845-858-1407
WIC	845-346-1300
Mental Health	845-291-2600
Social Services	845-291-4000
Adult & Children Services	845-291-2610
Child Protective	800-342-3720
Foster Adoption Home Finding	845-615-3620
Public Assistance/SNAP	845-291-4000
Child Abuse Hotline	800-342-3270
Veterans Service Agency	845-291-2470
Youth Bureau	845-615-3620
United Way	845-471-1900

Sullivan County

Offices and Departments:

Adult Protective Services	845-513-2390
Alcohol & Substance Abuse	845-292-5910
CASA	845-807-0672
Child Abuse & Maltreatment Reporting Center	800-342-3720
Office of the Aging	845-807-0241
Department of Social Services	845-292-0100
Mental Health Services	845-292-8770
Mid-Hudson Alcoholism Recovery Center	845-452-2368
Suicide Prevention	845-790-0911
Community Action	845-292-5821
United Way	845-794-1771

Ulster County

Offices and Departments:

CASA	845-339-7543
Child Abuse & Maltreatment Reporting Center	800-342-3720
Dutchess/Ulster County Office of the Aging	845-340-3456
Dutchess/Ulster County Dept. of Social Services	845-334-5000
Family Violence Services	845-334-5400
Ulster County Community Action	845-338-8750
United Way	845-331-4199

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845-561-6111

Hospiceoforange.com