

# Caregiver Guide



**HOSPICE** *of Orange & Sullivan Counties, Inc.*  
*In your home or in ours...it's about how you live.*

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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 nurses, social workers, pastoral care, volunteers and other contracted professionals 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.

## 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 own 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, don't 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 at this time.
- 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.

## **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.

## **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 have to 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.

## **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. A Dietician consult is available as needed. Please speak to your Hospice nurse.

### **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).
- Don't 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, don't force your loved one to eat. Remember that meal times 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.
- Remove strong odors and any clutter.
- 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 won't feel so helpless. If they cannot see well, help them locate the food on their plate according to the position of clock hands.
- Don't 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.
- **Don't 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.

### **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.

### **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 you're 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 mask or cannula clean, using a wet cloth to wipe it out.
- 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.
- If you can't 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.

## **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.

## **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 maintained at all times, 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 don’t skip meals, your resistance to disease will be better and you will have more energy. Don’t try to diet during this time. Try to watch your caffeine intake also.

- Delegate. Don't 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, clergyman, Hospice pastoral care or volunteer. 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. Remember that taking time for you is not selfish, and don't be afraid to laugh. You will find that laughing has healing powers. Make a list of the loved one's friends and invite them for "tea" or lunch.

### **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 Group.

### **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. Don't assume your loved one can't 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.
- 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 don't recognize you at times.
- Keep talking to them and reorienting them to time and place.

- Don't whisper to others within hearing of your loved one. They may think you are trying to hide something from them.
- Bowel and bladder control may be lost.
- Your loved one may sound very congested, like they have to 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. Don't 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. Don't try to force them to eat or drink.
- Urine output may decrease. If your loved one doesn't 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.**