In our society, most deaths do not occur in the home, and so, for many of us, death is a distant, frightening and sometimes mystical event. This pattern is changing and more patients and their families are sharing the death experience in the same home where they have shared their living experiences. One of the main goals of hospice care is to help patients live comfortably until they die and help the family live with them as they are dying.

The purpose of this booklet is to help you, the caregiver, in dealing with some of the problems and concerns that may arise when caring for a terminally ill person in the home. Take heart, you are doing a very important job; we hope this booklet will help you.
# Table of Contents

- **Introduction** .......................................................................................................................... 1
- **Family Emotions/Support Systems** .......................................................................................... 4
  - care for the caregiver
  - other family members
  - spiritual care
  - volunteers
  - social workers
  - friends
- **Activities of Daily Care** ........................................................................................................... 8
  - body hygiene
  - exercises
  - skin care
  - mouth care
- **Nutrition** ................................................................................................................................. 16
  - eating
  - liquids
  - tube feedings
- **Breathing Care** ....................................................................................................................... 22
  - shortness of breath
  - oxygen therapy
  - respiratory congestion
- **Pain Management** .................................................................................................................... 28
  - fears
  - what causes pain
  - types of pain medicine
  - assessing pain
- **Elimination** ............................................................................................................................ 34
  - urine elimination
  - catheter management
  - bowel elimination
  - diarrhea
- **Death Experience in the Home** ................................................................................................ 42
  - preparing for death
  - the physical signs of death
  - after death care
- **Important Phone Numbers** ..................................................................................................... 47
- **Pain Management Record** ........................................................................................................ 48
CARE FOR THE CAREGIVER

It is important to realize that although disease and its symptoms happen to the patient, illness has an effect on the entire family. Caring for the hospice patient at home can be rewarding; however, it is physically and emotionally draining for both the caregiver and the family.

During the illness, the patient at times may act angry or strange towards the caregivers. This can cause hurt feelings or anger on your part. In most cases, the patient’s lashing out actually means, “Why did this have to happen to me?” This behavior is most often directed towards the persons the patient knows will continue to love and care for them in spite of these bad moods. Try to realize that this anger is a result of frustration. If the patient does act angry or hostile, try to discuss your feelings with them. Be aware, however, that the patient may not realize that they are acting differently. You can share your fears and frustrations with members of the hospice team. They are there to help the entire family cope with this difficult time.

The physical demands of home care for the hospice patient are often strenuous. It is important that you, the caregiver, take time for yourself, as well as to take care of yourself. You’ll need moments of rest and relief if you are to keep physically and emotionally able to help the patient. Plan time for yourself to get out of the house. Other family members or friends can help, and sometimes they are just waiting to be asked.

Try to get at least six hours of sleep each night, and take naps while the patient is sleeping during the day. If you find that you are becoming exhausted, let your primary nurse know. The nurse may be able to suggest an easier plan to meet the patient’s needs. Using community help, or perhaps the services of a home health aide, are other alternatives. Try to remember that you are only one person and cannot do everything. Time spent on your regular responsibilities, such as household chores, yard work, and shopping should be lessened or may have to be taken on by others.
OTHER FAMILY MEMBERS

Each member of the family is unique and will deal with the patient and their needs in their own way. Although facing illness and death as a family makes it easier, not all families can be open and share their feelings. Sometimes sources outside the family (your nurse, social worker, minister, priest, rabbi or counselor) can help with the situation. They can help to bring family members together to talk, listen, and help one another.

Children have some special needs in dealing with illness and the impending death of someone they love. Depending upon their age and stage of development, death may have different meanings to them. It is important to answer their questions honestly and in a way they can understand. Having the children spend time with the patient as well as letting them help with the care of the patient is a good idea. This involvement will usually go a long way to lessen their fears. Children will need extra comfort, affection, and structure during this time since their normal routine has been upset.

SPIRITUAL CARE

For some hospice patients and their families, a religion, a church community, and their own personal relationship with God can be a strong source of strength during a difficult and searching time. You may want your local clergy or a pastoral counselor or minister from the hospice team to become more involved with your family at this time. Your primary nurse can help you to contact a clergy person if you desire one. The nurse can help to explain the patient’s situation to the clergy person before their first visit to your home. Although some families find meaning and comfort in their faith, others may not find religion to be a source of help. Neither approach is better than the other. Each person’s needs and beliefs are different and will be respected by the hospice team.
VOLUNTEERS

Most hospice programs have volunteers as part of the team to provide additional support to the patient and family. These volunteers are specially trained to work with dying patients and their families. They can offer you, the primary caregiver, a chance to get out of the house without having to worry about the patient. A volunteer may also provide companionship, and an open ear to listen to your fears and frustrations.

SOCIAL WORKERS

Most hospice programs have a social worker available to the patient and family. The social worker provides support and counseling to the patient and family as they attempt to deal with changes in their roles and relationships. Support may include help identifying community resources and providing advice concerning financial problems that occur with a prolonged illness. In addition, the social worker acts as a patient and family advocate in a variety of other ways, such as assistance in planning funeral arrangements.

FRIENDS

It is important to realize that some of your friends, as well as friends of the patient, will be able to provide support and assistance. Others will be unable to cope and seem to disappear out of your lives during this time. Those friends who want to help may need some direction from you. When they offer to help, make a simple request such as going to the store or fixing a meal. Sitting with the patient and sharing common fond memories can also be enjoyable and good for all.
ACTIVITIES OF DAILY CARE
BODY HYGIENE

It is a good idea to provide the bed-bound patient with a bath each day. This activity provides cleanliness and comfort and helps to refresh the patient in both body and spirit. A bath is usually given in the morning when they may have more energy to help; however, anytime during the day, as the patient prefers, is the best time.

Things You’ll Need

• large bowl and warm water
• soap and towels
• light bed cover to prevent chills
• skin protectant lotion, cream, or ointment

How to Do It

To avoid chilling the patient, only a small area should be bathed at a time. Gently soap the skin, then rinse and dry. Begin washing at the patient’s face and then work down towards their feet. Don’t forget to wash the back and apply lotion.

After washing the feet, the water will need to be changed before doing the buttocks area. Daily washing of the genital area is especially important since bacteria tend to collect there. Wash between the patient’s legs from the front toward the back. Rinse well and dry gently with a towel. A skin protecting lotion or ointment should be applied to this area if control of stool or urine is a problem.

After care of the genital area is completed, ask the patient to turn on their side so that the waterproof underpads and lift sheet can be changed. These should be changed daily or more often if they become dirty or soiled. If possible, bed sheets should be changed once a week.
This task usually requires two people. Flat bottom sheets are recommended, since they are easier to secure under the mattress.

**Things to Remember About Body Cleansing**

- If movement causes pain, give the patient pain medication about one hour before their bath.
- Ask the patient if you are rubbing too hard or too lightly; everyone has a different sense of touch.
- Provide privacy for the patient during the bath (close the door and drapes, reduce interruptions).
- If the patient is in a hospital bed, raise the level of the bed to lessen the strain on your back.
- Keep the patient’s body covered with a light blanket or sheet during the bath to avoid chilling.
- If the patient feels unable to tolerate a complete bath, try to wash the face, hands, back, underarms and genitals daily.
- Do not use powders, except under the arms; powder tends to cake in body creases. Instead, cornstarch can be sprinkled lightly between the patient and the linens.
- Brushing and styling the hair, as well as shaving can also be done around bath time. For some patients, attention to usual personal habits will help lighten their spirits.
If moving does not cause pain, then the patient’s arms and legs can be exercised during or after their bath. See Figure 1 for common passive exercises that can help maintain motion. Please check with your primary nurse before exercising the patient’s arms or legs.

Figure 1
SKIN CARE

It is important to try and keep the skin in good condition. Unfortunately, this is one of the most difficult problems in caring for bed-bound patients. Pressure sores (also called bed sores) often occur on patients who are confined to bed for a long time and don’t change position in bed often enough. Bed sores occur over bony areas of the body. Figure 2 shows areas most likely to develop sores.

Sometimes pressure sores can be prevented if the following steps are taken:

- Explain to the patient the importance of turning frequently.
- Provide pain medication as needed so that movement is easier.
- Use pillows to support the patient in a side-lying position.
- Keep the skin clean and dry.
- Keep the bed linens dry and wrinkle free.
- Very gentle massage around the reddened pressure areas is a good idea.
- Apply lotion around areas of pressure once or twice each day.

Figure 2
It is a good idea to check the patient’s skin for reddened areas each day during the bath. If you see redness over pressure areas tell your nurse, and the nurse will check them during the next visit. Your primary nurse may suggest the use of devices such as air, water, or egg-crate mattresses to help reduce pressure. In addition, sheepskins, heel and elbow protectors can be used to reduce friction as the patient moves about on the bed linens.

Even with the best care, skin breakdown may occur. Your primary nurse and doctor will suggest ways to treat these pressure sores and promote skin healing.

Additional Instructions
MOUTH CARE

Cleansing the mouth provides several benefits for the hospice patient. Regular care helps to prevent sores and may improve the patient’s appetite and desire to eat.

Things You’ll Need

- soft toothbrush and toothpaste
- small bowl
- dry cloth
- cool water
- mouthwash
- Vaseline®

How to Do It

The patient may be able to do this unaided and, if so, will probably prefer to be independent. If the patient needs assistance, raise the head and trunk to a half-sitting position to prevent choking and put a dry cloth under the patient’s chin. Give the patient a sip of water to moisten the inside of the mouth. Brush the teeth and gums gently with toothpaste, trying to thoroughly remove all food particles and crusted materials. The patient can then spit into the bowl and rinse with cool water, followed by a mouthwash rinse. Try to clean the patient’s mouth twice daily.

Denture patients should continue to follow their usual mouth care routine during illness. After eating, remove and clean the dentures. Gently clean the patient’s mouth with a soft toothbrush or cloth. Have the patient rinse with cool water, followed by a mouthwash rinse. As the patient loses weight, they may find their dentures no longer fit properly.
This may be caused by a change in the shape of the jaw. A poor denture fit may result in mouth sores. If refitting by a dentist is not possible, the dentures should be left out. Continue to provide mouth care twice daily.

After completing mouth care, apply a moisturizer such as Vaseline® to the lips and both corners of the mouth to prevent cracking. Reapply the moisturizer throughout the day as needed.

**Things to Remember About Mouth Care**

- Don’t put the toothbrush too near the back of the patient’s throat or the patient will gag.
- Do not give the patient mouth care as explained here if they are lying flat or are unable to swallow. The patient may choke on the liquid.
- If the patient cannot swish and remove liquid from the mouth, your primary nurse can give you special instructions for mouth care.
- If mouth soreness develops, tell your primary nurse. She will ask your doctor for medicine to treat the sores.

**Additional Instructions**

---

---

---

---

---
EATING

In times of illness, food intake is especially important. Food provides energy and the building blocks needed to sustain strength. For most of us, food is closely tied to life itself, but often appetite and food intake are lessened for the hospice patient. There are many possible causes for this loss of appetite.

How to Help

• Do not force the patient to eat or constantly remind them of their decreased appetite. Although an encouraging, gentle approach may help, the choice to eat is the patient’s.

• Serve the meal in a relatively comfortable, bright atmosphere. When feasible, eat in the room with the patient. Remove unpleasant odors and do not do unpleasant procedures around mealtime.

• Have the patient take a vitamin tablet each day to help meet their vitamin needs.

• Give mouth care prior to meals to freshen the mouth and stimulate taste buds.

• Appetite tends to decrease as the day goes on; make the most of breakfast time.

• Give pain medicines on a schedule to reduce discomfort before and during meals. For example, give pain medicine one-half hour prior to mealtime.

• Allow the patient to rest after meals, but keep the head of the bed elevated to promote digestion.

• Adjustments to the diet may have to be made if the patient can no longer wear their dentures. Soft foods or small bite-sized portions of meat, softened with gravy are recommended.

• If nausea is a problem, your primary nurse can talk to the doctor about ordering a medication to be given before meals to reduce nausea.
• Add small pieces of cooked meat to canned soup or casseroles to improve nutrient value in foods.
• Try new spices and flavorings for foods. It is common for a person’s preferences to change during illness. Add sauces and gravies to dry food.
• Try small frequent meals and leave a high protein snack or drink at the patient’s bedside. Your primary nurse can give you information and recipes for high protein supplements.

LIQUIDS

Liquids are also important for the body. They’re necessary to keep skin and mucous membranes moist and to promote the removal of the body’s waste products in the urine.

How to Help

• Don’t force liquids on the patient. A soft, encouraging approach is more effective; it’s the patient’s choice.
• Encourage intake of quality liquids as well as quantity. High calorie, high protein liquids provide both fluids and nutrition.
• Prune juice and fruit nectars not only provide calories but also help to maintain bowel function.
• Avoid liquids during mealtime. They may create an early sense of fullness.
• Make “double strength” milk by adding non-fat dry milk to whole milk. Blend well and chill.
• Use “double strength” milk instead of water for cooking cereals, diluting canned creamed soups, mixing puddings, and making instant cocoa.
• Soda straws or medicine droppers can be used to give liquids to patients who are weak or unable to hold a cup.
• Give liquids in other forms such as Jell-O, puddings, and ice cream.

Additional Suggestions:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
TUBE FEEDINGS

Sometimes a patient is unable to take food or medications by mouth. In some cases, nourishment can be given via a tube placed through the nose, down into the stomach, or directly through the skin into the stomach. Your primary nurse will teach you how to give tube feedings.

Name of feeding solution:

Amount given at each feeding:

How often to feed patient:

Special Instructions

_________________________________________________________________________

_________________________________________________________________________

_________________________________________________________________________

_________________________________________________________________________

_________________________________________________________________________

_________________________________________________________________________
Things to Remember About Tube Feedings

- Give the feedings at room temperature.
- Flush the tube before and after each feeding as directed.
- Change the tape and clean the skin around the tube each day. Your nurse will teach you how to change the dressing.
- Do not force food or medicine through the tube. If you meet resistance, attempt to flush the tube with water. Let your primary nurse know if you are unable to flush the tube.
- Before giving each feeding, you must check to see that the tube is still in the stomach.
- During feeding, as well as one hour after, the patient should stay in the sitting position.
- If the tube comes out, don’t panic. Call your primary nurse and she will replace it.
- A patient receiving tube feedings should continue to receive mouth care.

As the patient’s condition worsens, they will be taking in less food and liquids. This is usually more upsetting to the family than the patient who is no longer willing or able to continue to eat and drink. Trying to force a patient to eat will only cause conflict. It is a natural part of dying to begin to lose the desire to eat. Often a withdrawal from eating brings new awareness to the family of the patient’s worsening condition and impending death. It is important for you to discuss your feelings about this with members of the hospice team, so you can continue to be supportive of the patient’s right to choose, rather than acting angry or disappointed.
BREATHING CARE
SHORTNESS OF BREATH

For a patient who is very ill, the process of getting air in and out of the lungs can be difficult at times. Breathing difficulties are often referred to as “shortness of breath” or “air hunger.” These difficulties can create a decreased oxygen level in the body. Signs of low oxygen may include a restless or anxious feeling, as well as a faster breathing rate. If these symptoms occur, there are some things you can do to help the patient breathe easier.

Things You Can Do to Help

• Be calm and reassuring.
• Raise the head of the bed or place more pillows behind the back and head.
• Have the patient sit up and lean forward. This position will help the lungs fill more easily.

OXYGEN THERAPY

Your primary nurse will check the patient’s breathing during each visit. Tell your nurse if you or the patient have noticed any breathing problems. If breathing problems exist, the nurse will discuss the possible need for oxygen. If oxygen therapy is needed, the doctor will decide how much the patient will need. The nurse will contact a medical supply company. The company will set up the oxygen therapy equipment and explain to you how to use it.

Two common ways of giving oxygen therapy are by face mask or nose cannula. Both of these devices increase the amount of oxygen available for the patient to breathe.
Things to Remember About Oxygen Therapy

• Remove and clean the mask as needed.
• Do not smoke or light matches in a room where there is oxygen in use.
• Do not use oxygen around a gas stove.
• Place small cotton pads between the tubing and the skin to lessen irritation.
• The face mask must fit snugly on the patient’s face.
• The prongs of the nasal cannula must be in the patient’s nose.
• Watch your supply of oxygen; make sure you have a 24-hour supply, especially on the weekends.
• Carefully follow the instructions given by the supplier to ensure that the equipment will work properly.
Type of oxygen set up: ________________________________________________________

How much (flow rate): _______________________________________________________

Who to call with problems: __________________________________________________

Phone number: _____________________________________________________________

☐ Nasal cannula  ☐ Face mask
RESPIRATORY CONGESTION

Respiratory congestion is identified by noisy, moist breathing. As patients become weaker, there is often a decreased cough reflex and secretions may collect in the airway. It can be very distressing for the patient and family, since it may appear that the individual is drowning or suffocating from his or her own secretions. Although this symptom most commonly occurs when a patient has a decreased level of consciousness, if the person is alert, the respiratory secretions can cause the patient to feel extremely agitated and fearful of suffocating.

Things You Can Do to Help

Notify the hospice/palliative care team to ensure appropriate medications are ordered. Your primary nurse will assess the patient to determine potentially treatable underlying causes, including infection or inflammation. If physical findings suggest congestive heart failure, for example, the hospice team may start diuretic therapy for fluid overload; if pneumonia is present, antibiotic therapy will be initiated. If the onset is sudden and associated with acute shortness of breath and chest pain, it might suggest a pulmonary embolism or myocardial infarction.
How to Manage

• Simple repositioning of the patient may help him or her to clear the secretions.¹

• If secretions can be easily reached in the mouth or throat, suctioning may be appropriate. Deep suctioning should be avoided since it can be very uncomfortable for the patient and cause significant agitation and distress.¹,²

• Pharmacological interventions or management are effective and may prevent the need for suctioning. If possible, primary treatment should be focused on the underlying disorder and/or appropriate to prognosis and the wishes of the patient and family.¹

Additional Instructions

__________________________________________________________________________________________

__________________________________________________________________________________________

__________________________________________________________________________________________

__________________________________________________________________________________________

__________________________________________________________________________________________

__________________________________________________________________________________________
PAIN MANAGEMENT
FEARS

The fear and reality of pain are often major problems for the hospice patient. Most experts on pain encourage us all to trust the patient and believe that the pain is something that the person experiencing it knows the most about. Therefore, the patient can best tell the doctor and nurse how effective the different ways of relieving pain have been. Your primary nurse will take the information that the patient (and you) are able to report about the pain experience, and use that information to work with you and your doctor to develop a pain management plan suited for the patient’s needs.

During one of the first visits, your primary nurse will ask the patient some questions about their pain. It is important to encourage the patient to be honest about how bad and how often they feel pain. Many people report less pain than they are having. There are many reasons why this happens. Many people fear that an increase in pain means the disease is worsening, or that feeling pain and illness go hand-in-hand and must be tolerated. In addition, some religious beliefs hold that pain is either a punishment for past sins or a method of achieving salvation in the life beyond. Some cultures encourage people to be silent about their pain. Finally, fear of addiction to medications or fear that the use of strong pain medicine now will prevent good relief in the future if the pain worsens, may be reasons for reporting less pain. These reasons should be openly discussed, as they are often strong influences on the patient’s ability to share and evaluate their pain.

It is important to remember that patients who have long-term pain will not act the same about their pain as someone who has new pain. The person with long-term pain may not show many of the signs we are used to seeing in people with pain. For example, they may not speak or moan about the pain, or may not be restless. Heart rate and breathing may not increase as expected. Just because the patient doesn’t act like they are in pain doesn’t mean the patient is not having pain. For these reasons it is important that you and the patient speak very openly and honestly with your nurse and doctor about the patient’s pain. The doctor
and nurse can only effectively work with you and the patient to control or lessen the pain if you are open with them.

**WHAT CAUSES PAIN**

Pain appears to have a physical cause, meaning that some part of the disease is causing pain messages to be sent to the brain where pain is realized. It is important to try and discover the cause of the pain, but this is not always possible. This does not mean, however, that the pain is not real.

**TYPES OF PAIN MEDICINE**

There are many different kinds of pain medicine.

Pain medicines are most commonly available as pills, liquids, transdermal patches, rectal suppositories, and injections. The amount and type of pain medicine the patient should take will be decided by the doctor after talking with the patient and the primary nurse. It is important that the patient tell the doctor about the relief received or not received from the pain medicine. Your primary nurse may ask you and the patient to keep a written pain record between visits (see page 48). This record will help in making necessary adjustments in the pain management plan. Questions regarding pain medicine should be discussed with the doctor or primary nurse.

There are other ways to help lessen the patient’s pain. These may be used along with the pain medications. Some methods include distraction, massage, relaxation exercises, and the application of heat or cold near the painful area.
ASSESSING PAIN

Everyone expresses pain differently. Although some patients may talk freely about their pain, others may feel uncomfortable discussing the issue.

If you suspect the patient is suffering, it is important to ask about pain. A good way of asking is to say: "How would you rate your pain level right now on a scale from 0 to 10, with 0 being no pain and 10 being the worst pain you ever had?"

Other questions might include:

- Is it a new pain or has it happened before?
- Where is it located? Is it in more than one area? If so, which location is most bothersome?
- Is the pain sharp and stabbing or dull and aching?
- If the patient is taking pain medicine on schedule, were there times during the day that the patient experienced "breakthrough" pain? How many times did this happen today?
- Did the patient sleep through the night without pain?

In assessing the patient’s condition, it may also help to look for behavior or body language that could be a response to pain, because the patient may be unwilling or unable to communicate about pain in words.

Behaviors to look for include: eyes that are closed tightly, knitted eyebrows, crinkled forehead (grimacing), clenched fists, groaning when moved or a stiffened upper or lower body that is held rigidly and moved slowly. Other signs may include rubbing certain parts of the body, slouched or bent posture, and avoiding sitting or standing.
Things to Remember

The doctor and primary nurse need to know if the patient’s pain has increased or become different in any way so that they can ensure the patient receives the correct medicine and remains as comfortable as possible. The following symptoms should be reported to the patient’s primary nurse or doctor so that they can address how to best treat the pain if it has changed in any way:

• No relief after taking pain medicine as prescribed
• Some pain relief, but there is still a lot of pain 1 or 2 days after starting the medicine
• A new type of pain, pain in new locations, or new pain when moving or sitting
• Adverse side effects of pain medicines
• Changes in sleep
• Difficulty coping with pain – for example, if the patient becomes anxious, depressed, or irritable

The doctor will determine the proper amount of medicine for the patient. Questions regarding pain medicine should always be discussed with the doctor or primary nurse.
Your primary nurse will mark on this figure acceptable areas to give the patient shots.
ELIMINATION
The elimination of urine and stool is the body’s mechanism for removing waste products. Problems with elimination can cause the patient a great deal of anxiety, embarrassment, and discomfort. This is often a source of worry for the hospice patient.

**URINE ELIMINATION**

Urine is a liquid composed primarily of the body’s waste products dissolved in water. For this reason, it is important for the patient to attempt to drink a substantial amount of fluid in order to maintain a good urine flow. For the bed-bound patient, a bedpan (women) or a urinal (men) will be needed to collect the urine.

For some patients, the ability to control urination is lost. In other patients, the passageway for urine is blocked. If either of these conditions is present, it may be necessary for the nurse to place a catheter (tube) into the patient’s bladder to drain the urine. This should only be done under the direction of your doctor following a discussion about the procedure with the patient. If it is decided that a catheter is needed, your nurse will put it in place and teach you how the system works and how to take care of it.

For some patients, diapers or external catheters (male patients only) may be used. Usually these are not good long-term solutions for urine elimination problems. You and the patient should discuss these options with your primary nurse and decide which method is the best choice for the patient.
Things to Remember About Urine Drainage Systems

- Always wash your hands before and after working with the catheter or drainage bag.
- Check the drainage tubing for any kinks, and make sure the drainage bag is below the level of the patient to encourage draining by gravity.
- Check for any leaking around where the catheter enters the body. If you see leakage around the catheter, let your primary nurse know.
- The drainage bag should be emptied one or more times per day.
CLEANING THE CATHETER ENTRANCE AREA

It is important to clean the area around where the catheter enters the patient’s body once a day to protect the skin and prevent infection.

Things You’ll Need

- warm water in a basin
- soap and towel
- antiseptic solution
- cotton balls

How to Clean the Catheter

- Begin by washing the area around the catheter entrance gently but thoroughly. Rinse the area with warm water and then pat dry. Finally, wet a cotton ball with antiseptic solution and swab the catheter entrance site.
IRRIGATING THE CATHETER

Sometimes the catheter may become blocked. The flow of urine can be restored by irrigating the catheter. Catheter blockage should be suspected if urine flow has stopped, there are no kinks in the line, and the collection bag is below the level of the patient. After obtaining the approval of your doctor, irrigate the catheter. Your primary nurse will teach you how and provide you with the necessary supplies.

Things You’ll Need

• irrigation tray and syringe
• alcohol wipes
• sterile saline solution

How to Irrigate the Catheter

1. Wash your hands well.
2. Place a waterproof bed pad under the work area to protect the bed linens from any spilled urine.
3. Pour sterile saline into the irrigating container (about ½ cup).
4. Remove the cover tip of the syringe (remember not to touch the tip of the syringe – it’s sterile). Keep the cap nearby.
5. Draw the saline solution into the syringe, then put the cap back onto the syringe to keep it sterile.
6. Cleanse the connection site with an alcohol wipe.
7. Separate the tubing from the bag and remove the cap from the syringe. Push the tip of the syringe into the catheter until it fits snugly.

8. Gently push the solution into the catheter. If you meet a lot of resistance, stop and reconnect the tubing to the catheter. Notify your primary nurse.

9. If the solution goes in easily (as it should), disconnect the syringe and let the catheter drain into a basin.

10. Reconnect the catheter to the drainage bag tubing.
**BOWEL ELIMINATION**

Bowel habits differ from person to person. Some people move their bowels once a day, while others may only move theirs 2-3 times a week. In the hospice patient, many things may cause a less frequent bowel movement and difficulty passing stools, leading to constipation. The best treatment for constipation is prevention. A plan for prevention includes:

- Try to maintain well-balanced meals.
- Set aside a time each day (usually after breakfast) that the patient sits for a period of time on the bedpan, commode, or toilet.
- Maintain fluid consumption to two quarts a day (unless otherwise instructed by your doctor).
- Try to consume plenty of nectars, juices, and Jell-O.

If prevention efforts don’t work, and the patient has not had a bowel movement for 1-2 days, tell your primary nurse. Your nurse will want to know what has worked for the patient’s constipation in the past, and may suggest nonprescription laxatives, which are available over the counter.

**DIARRHEA**

Diarrhea can also be a problem for the hospice patient. It is characterized by frequent watery stools and is often accompanied by stomach cramping. If the patient has diarrhea, you should keep a record of the frequency of stools. Your primary nurse will try to find the cause for this diarrhea and will talk with the doctor about a medicine to treat it. Some medicines can be obtained without a prescription, while others will require a prescription.
Things to Remember When a Patient Has Diarrhea

• Keep the bedpan close to the patient to avoid accidents.

• Place a waterproof bed pad under the patient. If stool leakage should occur, the pad may help to prevent additional changes of the entire bed.

• After each loose stool, the rectal area should be washed with mild soap and water and a skin protection lotion should be applied.

• Encourage the patient to increase liquids if diarrhea occurs.

• The patient can drink juices or liquid diluted Jell-O for both fluid intake and to provide some sugar for energy.

• If the patient is too weak and can’t get to the bathroom, then it will be necessary for the patient to use either a commode (a chair with a bedpan inserted in the open center) or a bedpan.

Things to Remember About Using Commodes and Bedpans

• Warm a metal bedpan by running warm water over it prior to use.

• Put a towel on the back side of the bedpan for padding.

• Sprinkle baby powder or cornstarch around the top of the bedpan so that the patient’s skin will not stick to it.

• Keep the commode near the bed and help the patient to get on and off of it.

• If the patient is bed-bound, it is important to try and put them in a sitting position for elimination by raising the head of the bed.

• Remember to wash your hands after helping the patient with elimination and to wash the patient’s hands as well.

• Give the patient time alone during elimination.
DEATH EXPERIENCE IN THE HOME
PREPARING FOR DEATH

Just as each person’s life is unique, so is his or her death. Because of this, it is difficult to give hard facts about what the actual death of the patient will be like when it happens. Instead, some common concerns and approaches will be shared in this section.

Although difficult, it is a good idea for some pre-death arrangements to be made by the patient and the family. This topic can be difficult to bring up, as it is another way of acknowledging the patient’s approaching death. Your primary nurse and social worker can help open discussions on this topic.

The patient can provide for survivors and prevent legal problems for the family after his or her death by having a current well-prepared will. Your social worker can give you advice about whom to contact to draw up a will or to make changes in a current will.

Making funeral plans before the patient’s death may seem morbid to you. However, it is a good idea to contact the funeral home you plan to use and discuss with them the patient’s and your wishes for funeral arrangements. Although it is difficult to discuss this with the patient, involving him or her in planning for what could be a meaningful service can provide reassurance that you have acted according to the patient’s wishes.
THE PHYSICAL SIGNS OF DEATH

Many caregivers wonder about the changes that occur in the patient just before death. They want to be prepared and take the right actions. Unlike the way death is portrayed in the movies, the patient usually slips into death similar to how they have fallen asleep each night of their lives. It is unusual for someone to convulse or hemorrhage just before they die, although this can happen.

There are some common signs seen in near-to-death patients. The skin becomes very cool, particularly in the arms and legs, and may feel clammy, damp or appear bluish. The number of times and how deeply the patient breathes will lessen until the patient stops breathing entirely. Breathing may become noisy due to mucous collecting in the throat. Decreased movement and loss of strength can be observed and sensation is gradually lost. Awareness will vary; the patient may or may not be conscious. Hallucinations may occur, or the patient may become restless or very anxious. Some or all of these changes may be seen in dying patients. Although watching their declining condition may be difficult for you, the patient is usually unconcerned about these changes.

Sometimes “active dying” occurs over a period of hours or days. Even when many of these signs are present, it is difficult to predict the amount of time before death will occur. Some patients will exhibit some of these changes and then for some unexplained reason their condition may begin to improve a little. Although the family is caring and loving towards the patient, these roller-coaster changes can be emotionally and physically exhausting for the caregiver.

Usually in the weeks and days prior to the death, your primary nurse will begin to visit more often and other members of the hospice team will increase their availability and support. As the patient’s condition worsens and they begin to emotionally as well as physically withdraw from this world, caregivers can suffer from feelings of helplessness. Withdrawal is normal for the dying patient as he or she becomes less concerned about his or her surroundings. At
this time, many of the tasks mentioned earlier in this booklet will no longer be appropriate. Alternative ways to keep the patient comfortable might include a sponge bath and moistening the lips with cool water. Holding the patient’s hands can be very meaningful and comforting at this time. It is important to continue to talk to the patient and offer reassurance. Simply saying, “I’m here, I’ll be with you” can offer the patient great support and comfort.

Tell visitors and other family members not to speak in front of the patient as if he or she isn’t there, even if the patient appears to be sleeping. Nothing should be said that would distress the patient should the conversation be overheard.

When you feel that death is near, it is a good time to bring the family members together, since they may have some last thoughts or expressions of love to share with the dying person. You should also call your doctor and primary nurse to let them know that the patient’s death is approaching. You will know that death has occurred when the patient stops breathing for several minutes and the heart is no longer beating.
AFTER DEATH CARE

Soon after the patient dies, you should notify the funeral director so that he or she can come to your home and remove the patient’s body. In some communities, the patient’s body must be taken to the hospital so that a doctor can officially/legally pronounce them to be dead. Your primary nurse and doctor can give you information about the usual procedure in your area.

The final goal of hospice care is to help the family go on living after the patient’s death. This means the members of the hospice team will continue to keep in touch with you and your family through visits and phone calls.

Often the period right after the patient’s death is a time of regrouping and relief in the family. One should not feel guilty about the sense of relief. Later, more active grieving and sadness may occur and members of the hospice team are available to help you through this difficult time.
IMPORTANT PHONE NUMBERS

Doctor: _______________________________________________________________________

Nurse: _______________________________________________________________________

Pharmacist: __________________________________________________________________

Social Worker: __________________________________________________________________

Volunteer: ___________________________________________________________________

Hospital: _____________________________________________________________________

Ambulance: __________________________________________________________________

Medical Supply Co.: ____________________________________________________________

Clergy: _____________________________________________________________________
# PAIN MANAGEMENT RECORD

<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>Drug</th>
<th>Dose</th>
<th>Pain</th>
<th>Pain Site</th>
<th>Relief</th>
<th>Side Effects/Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Pain Rating**

1 = mild  
2 = discomforting  
3 = distressing

**Relief Rating after 1 Hour**

0 = no relief  
1 = slight relief  
2 = moderate relief  
3 = lots of relief  
4 = complete relief
This booklet was compiled with
the gratefully acknowledged assistance of

Anne Rooney, MS, RN
Marilee I. Donovan, PhD, RN
Valerie Wodzinski-Sasek, RN, MSN
Ellen H. Elpern, RN, MSN
The Nursing Staff of
Community Nursing Service, Proviso-Leyden
Mrs. Janice O’Donnell
Mrs. MerryLou Dotson

References