

# BJC Palliative Care & Hospice

# Caregiver Instruction Manual

“There are four kinds of people in the world:

Those who have been caregivers,  
Those who are currently caregivers,  
Those who will be caregivers, and  
Those who will need caregivers.”

*~Rosalynn Carter*

*Helping Yourself Help Others*

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# **1) CARING FOR SOMEONE IN BED**

As patients become weaker, they stay in bed or chairs longer. Moving and changing positions can ease some of their discomfort, relieve pressure and help prevent skin breakdown. Changing positions every two hours helps prevent pressure sores and stiffness.

When moving patients, explain what you are doing in order to reduce their anxiety in being moved, so they can cooperate and let you know how they would like to be turned. Provide pain medication approximately 30 minutes to an hour prior to movement, if moving is uncomfortable for the patient. Keep any tubing free from being blocked or pulled. Using two people to move someone is easier than one. (NOTE: If you have questions about any instructions or suggestions contained herein, the nurse/home health team will be happy to explain and demonstrate for you.)

## **A. BODY MECHANICS**

1. Avoid twisting your back or trunk; use your legs and feet to turn in place.
2. Lift with your legs, not your back.
3. Bend or flex knees; use legs and stomach muscles.

## **B. BODY HYGIENE**

Baths provide cleanliness and comfort, and may be given at any time.

### **1. ITEMS NEEDED FOR BATHING**

Large basin of warm water ▪ Soap, washcloths, and towels  
Lightweight sheet to cover patient during bath ▪ Skin care lotion

### **2. TIPS FOR BATHING**

- If the patient experiences pain with movement, give the prescribed pain medication about one hour before bathing.
- Provide privacy for the patient by asking others (who are not helping) to step out of the room. Also, remember to close drapes and doors.
- If you are using a hospital bed, raise the bed to reduce the strain on your back. If the patient cannot tolerate a bath

everyday, focus on important areas—face, hands, back, underarms, and genitals.

- To avoid chills, wash small areas at a time while keeping other areas of the body covered with light linens.
- Begin at patient's face and work toward the feet. Soap the skin gently, rinse, and dry with towels.
- Turn the patient on a side to wash the back. Apply lotion to dry skin areas as well as the back.
- The genital area should be washed last. Washing this area daily is important to prevent bacteria growth and skin irritation. Wash area in between the legs front to back—rinse and dry well.
- Shaving, brushing, and styling hair can improve patients' spirits and can be done around bath times.
- When giving a bath inspect the skin for redness or open areas. Notify the hospice nurse of any changes.
- Do not use powders after bathing; they cake on the skin and can cause irritation.

### **C. CHANGING BED LINENS**

1. Linens should be changed as needed or at least every third day. If the patient has lost control of bladder and/or bowel function, check the sheets, bedpad, and change if dirty. Cloth underpads (bedpads) can be purchased at medical supply companies or handmade.
2. To change the linen, turn patient on his/her side and roll dirty linen close to patient. Place the clean linen on the bed and roll close to dirty linen, being careful not to soil the clean linen. Turn the patient over the rolls of linen and continue process until dirty linen is removed and clean linen is in place.

### **D. USE OF PULL/ROLL SHEET**

1. A folded sheet placed under the body can be used to move the patient around in bed.
2. Always support the head if the patient is unable to do so.
3. Two people can move a person up in the bed by rolling the sides of the sheet up close to the person's hips and together moving the person up in the bed.
4. One person can use the sheet to move a person onto their side.

## **E. ADJUSTING THE PATIENT'S POSITION**

1. When turning the patient to the near side of the bed, begin with the head, then the shoulders, trunk, legs, and feet.
2. When moving from side to side, bend the patient's knees. This helps the rotation of the hips, and the body will follow.
3. When the person is in the new position, support the arms and legs with pillows or rolled up towels.
4. If the person cannot communicate, imagine yourself in that position. Check that the shoulder/arm is not pinned beneath the patient.
5. Keep skin clean and dry. Keep bed linens and clothing dry and wrinkle free.
6. A nurse should check any reddened areas or opened areas of skin.
7. Apply lotion and massage the skin to increase circulation and general comfort.

## **F. WHEN MOVING SOMEONE FROM THE BED TO A CHAIR:**

1. Place the bed in a low position
2. Assist the patient to the strong side, if there is one
3. Always lock/secure the bed, wheelchair or chair to prevent movement
4. Stand in front of the person being transferred with your feet apart to improve your balance and control.
5. Help the person lying in the bed to a sitting position and let any dizziness subside.
6. Use your legs, not your back, to lift.
7. Standing in front of the person, place your arms around the body, with your hands on their ribs in back.
8. Tell the patient to put their hands on your shoulders (not around your neck).
9. Make sure the patient's feet are on the ground before you begin to gently rock the person into a standing position.
10. To turn, maintain your wide stance for balance, pivot on your feet, and slowly turn your whole body.
11. Gently lower the person into the chair by bending your knees.

## **G. SKIN CARE**

One of the most difficult problems in caring for a patient who is bed-bound is maintaining good skin condition. When a patient is bed-bound, there is a potential for pressure sores (bedsores) to develop. Pressure sores occur when a patient remains in the same position for extended periods of time.

## **H. AN OUNCE OF PREVENTION**

- Encourage the patient to turn frequently and assist as needed.
- If movement is painful for the patient, then give pain medication one hour before turning the patient.
- Use pillows between patient's legs when the patient is laying on his/her side.
- Elevate feet to relieve pressure on the patient's heels by placing a towel roll or pillow under ankles.
- Turn the patient every two hours **while awake**.
- Your hospice nurse can provide instruction on proper turning techniques.
- Elevate the patient's head to 30 degrees when the patient is short of breath.
- Gentle exercises can increase and stimulate circulation, improve appetite and promote a sense of well-being. The hospice nurse can instruct you on these exercises.
- Even with the best skin care, breakdowns in patient's skin can still occur. Your hospice nurse will offer suggestions on how to best care for skin breakdown.
- Washable or disposable bed pads can promote ease in keeping a clean, dry bed.

## **I. ORAL CARE**

A clean mouth can improve the patient's sense of well being, improve appetite, and prevent mouth sores.

### **1. ITEMS NEEDED FOR ORAL CARE**

Soft toothbrush or Toothette ▪ Toothpaste ▪ Cool water ▪ Small basin  
Wash cloth ▪ Lip balm

### **2. HOW TO DO ORAL CARE**

- a. If patients can do their own mouth care, encourage them to do so. If assistance is needed, raise patient to a sitting position and place a dry towel under his/her chin. Moisten the mouth by giving patient a sip of water. Gently brush teeth to remove food and other materials. After brushing, rinse the mouth by having the patient take another sip of water and then spit in the small basin.

- b. Patients with dentures should follow their normal routine. Remove and clean dentures at least once a day. After denture removal, the mouth can be rinsed and cleansed with a soft toothbrush. Rinse with cool water or mild mouth rinse.
- c. When a patient loses weight, dentures may fit improperly. If dentures do not fit properly, remove them to prevent mouth sores; however, continue to rinse the mouth as described above.

3. **A FEW REMINDERS**

- a. To avoid gagging, do not push toothbrush too far back into mouth.
- b. If the patient is unable to swallow or is unconscious, do not give mouth care except as instructed by your hospice nurse.
- c. If you see mouth sores, (white patches in the mouth) notify the hospice nurse.
- d. To remove dentures, slide a gloved finger to the back edge of the top denture to release the suction; remove from the mouth. Next, remove the bottom denture plate.

## **II. URINE ELIMINATION**

### **A. WHAT IS BLADDER INCONTINENCE?**

Loss of bladder control causing loss of urine; the problem has varying degrees of severity. Some people have only small, minor leaks or dribbles of urine, while others lose large amounts of urine at a time. Bladder muscles, nerves, and the brain all work together to control bladder function, and a problem in any of these areas can result in incontinence. Infection, constipation and mobility problems can also cause incontinence. Urine left on the skin can lead to irritation and odor.

### **B. WHAT CAN BE DONE TO CONTROL THE URINARY LEAKAGE?**

- Establish with the patient a regular pattern of urinating, using the toilet every two hours during waking hours.
- Make it easier for the patient to get to the bathroom by moving closer to the toilet, or using a bedside commode, urinal or bedpan.
- Protect the patient's privacy and dignity.
- Suggest that the patient avoid fluids or foods that contain caffeine (soft drinks, coffee, tea or chocolate) and alcohol which can over stimulate the bladder.
- Ask your nurse about exercises that can help develop more control or medications that may help improve bladder function. Sometimes a catheter is used to drain the urine from the bladder, but catheters are not right for everyone. They can increase the risk for infection.

### **C. PROBLEMS WITH URINE ELIMINATION CAN CAUSE THE PATIENT MUCH DISCOMFORT AND ANXIETY.**

- Because urine is needed to dispose of body waste, it is important for the patient to attempt to drink the recommended 6-8 glasses of fluid each day or as much as they can tolerate.
- A patient who is bed-bound will need to use a bedpan or urinal. For some patients, diapers may also be helpful.
- In some patients, control over urination is lost or the passage way may become blocked. In these situations, it may be necessary for the nurse to insert a catheter (tube) into the patient's bladder to drain the urine.
- The nurse will give instructions on how to care for and drain the catheter bag.
- Remember, it is important to keep the genital area clean and dry to prevent skin irritation.

- Notify your nurse if the urine changes color, the catheter comes out or is pulled out, or no urine or very little urine is noted over a 2-3 hour period of time.

#### **D. WHAT CAN BE DONE TO PREVENT ODOR OR SKIN IRRITATION?**

- Keep the skin clean and dry; products are available that can help you feel clean and eliminate odor. (Ask your hospice nurse for suggestions.)
- Use barrier creams to protect the skin and protective products to help keep clothing dry.
- The nurse can help you select which type of garment and products would be most helpful to use.
- Change garments frequently.
- Wear gloves and always wash your hands before and after care to help prevent infection.

#### **E. WHAT TO DISCUSS WITH THE NURSE?**

Notify the nurse of changes in bladder function including burning, pain or discomfort with urination, and changes in the amount, color or odor of urine; make the nurse aware of any skin irritation.

#### **F. FOLEY CATHETER**

What is a Foley catheter? A Foley catheter (also called an indwelling catheter) is a thin rubber tube, which is placed in the bladder and used to drain urine out of the body. After the catheter is inserted, its tiny tip can be filled with sterile water to make a small balloon which holds the catheter in place and keeps it from slipping out of your bladder. A Foley catheter can be used for a short or long time.

Why is it used? Sometimes, when a patient is very weak and cannot get up, a Foley catheter is inserted for comfort and convenience. It is also used when a patient is unable to urinate on his/her own, or retains urine.

#### **G. DAILY CARE OF FOLEY CATHETER**

Follow these steps every day to help prevent a bladder or kidney infection, and keep the patient comfortable. **Always wash your hands with soap and warm water before and after catheter care.**

- Clean the skin around the catheter at least once each day and after every bowel movement (BM).
- Always keep the urine bag below the level of the bladder which is about waist level. Keeping the bag below this level will prevent urine from flowing back into your bladder from the tubing and urine bag. Backflow of urine can cause an infection.
- Do not tug or pull on the tubing. This can cause bleeding and hurt the urethra. Be careful to keep the tubing from being under step when the patient is walking; the tubing can be held curled in the hand with the urine bag low when walking. You may also want to clip or pin the tubing to the patient's clothing.
- Place the catheter tubing so it does not kink or loop. When the patient is in bed, hang the urine bag beside the bed, making sure the bag is below the level of the bladder. If you use movable bed rails, do not hang the urine bag on the bed rail. Instead, hang the bag on the frame of the bed.

## **H. EMPTYING THE DRAINAGE BAG**

A drainage bag or catheter bag should be emptied only when it is full enough to be necessary. Typically, empty full-sized bags every 8 hours and smaller (leg) bags every 3 to 4 hours, or sooner if they fill up. The following steps are to be used when emptying the drainage bag.

1. Place a large plastic or metal container on the floor next to you, or you may empty urine into a toilet.
2. Wash your hands with soap and water before emptying the bag
3. Without touching its tip, remove the drain spout from its sleeve at the bottom of the catheter bag. Open the slide valve on the spout.
4. Let the urine flow out of the urine bag into the container or toilet. Do not let the drainage tube touch anything.
5. When the bag is empty, clean the end of the drain spout with water and tissue. Close the slide valve and put the drain spout back into its sleeve at the bottom of the urine bag.
6. Wash your hands with soap and water.
7. If the catheter does not drain, or appears to be “plugged” or not draining, please call the nurse.

## **BOWEL MOVEMENTS**

Bowel habits vary from person to person. As time progresses the patient may develop changes in bowel habits.

### **A. CONSTIPATION**

What is constipation? Constipation means that bowel movements occurring less often than the normal pattern for the individual, hard stool is produced, or there is increased difficulty moving bowels.

What should be reported to the hospice/palliative care team? If the patient has no bowel movement in 2 days or a change in the frequency of bowel movements; pain, cramping or tenderness or a feeling of fullness or bloating; nausea and/or vomiting; blood in stools; and diarrhea or oozing of stools should all be brought to the attention of the nurse.

It is very important to have a plan to prevent constipation.

- Try to maintain the patient's intake of well-balanced meals.
- Set aside time each day that the patient spends time on the bedpan/ bedside commode/ or toilet.
- Encourage the patient to drink 6-8 glasses of fluid a day. Allow patient to drink what they can tolerate.
- If the patient has not had a bowel movement in 2-3 days, inform your nurse. The nurse will suggest a bowel regimen.
- Pain medications sometimes constipation. If the patient is taking pain medications, the nurse will suggest daily bowel regimens to prevent constipation.
- Record when bowel movements have occurred
- Drink as much fluid (liquids) as is comfortable. Drinking warm liquids has benefited many patients.
- Consume more fruits and fruit juices.
- Increase physical activity if possible. Walking even short distances can be beneficial.
- Sit upright on toilet, commode, or bedpan.
- Establish routine times for toileting.
- Take laxatives/stool softeners as ordered by healthcare provider. Avoid bulk laxatives if not taking in enough fluids.
- Notify hospice/palliative care team if constipation continues.

## **B. DIARRHEA**

Diarrhea can also be a problem for the hospice patient. Frequent, watery stools often accompanied by stomach cramping characterize diarrhea. You should keep a record of frequency of diarrhea. Your nurse and your physician will decide if medications need to be ordered to help control diarrhea.

## **C. WHAT CAUSES BOWEL INCONTINENCE?**

Not being able to control a bowel movement from the rectum is called bowel incontinence; cramping, loss of appetite and fecal leakage may be symptomatic. The condition has many causes including:

- Weakness of the anal muscle
- Not moving around, lack of exercise
- Nervous system disorders
- Long-term use of laxatives
- Not enough fluid intake
- Hemorrhoids
- Sedation
- Severe constipation may also lead to leakage from the rectum

## **D. WHAT TO DISCUSS WITH THE HOSPICE/PALLIATIVE CARE TEAM?**

1. Medications and diet history
2. Changes in activity level
3. Color, looseness and odor of the stool
4. Abdominal discomfort, cramping or bloating
5. Skin problems developing in the affected area
6. Patient and caregiver concerns or worries

## **E. WHAT CAN BE DONE FOR BOWEL INCONTINENCE?**

1. Know the patient's bowel history and usual routine regarding time of day, following a meal, etc.
2. Plan a bowel-retraining program that is easy and fits into the patient's lifestyle. Your nurse can help develop the plan.
3. Assure that the patient takes in enough fluids and fiber if possible.
4. Provide ample time and privacy during toileting.
5. Keep skin clean and dry to prevent odors and skin breakdown. Avoid use of baby powder and cornstarch.
6. Be sure the patient wears loose fitting clothing to allow for air flow and protective garments as appropriate.
7. Control odors with fresh air and room deodorizers.
8. Avoid offering the patient foods that can act as laxatives such as caffeine, alcohol, diet soda or artificial sweeteners.

9. Use Depends or similar products or liners to ease in keeping patient and bedclothes clean.
10. Talk to your nurse for other ideas or for more information.

**F. USING BEDPANS OR BEDSIDE COMMODES**

1. Keep the bedside commode near the bed if one is in use.
2. Put a towel on the back of the bedpan for padding.
3. Sprinkle baby powder or cornstarch around the top of the bedpan so the patient's skin will not stick to it.
4. If the patient is bed-bound, it is important to try to put him/her in the sitting position for bowel movements by raising the head of the bed.
5. Use rubber or latex gloves and remember to wash your hands and the patient's hands after helping him/her.
6. Give the patient ample time while using a bedpan/bedside commode.

### III. NUTRITION/HYDRATION

Frequently, appetite and food intake decreases during the course of an illness. Your nurse can instruct you about these changes and what you can do about them as is appropriate for your individual circumstances.

In normal situations after an injury, illness, or surgery a physician can provide the patient with artificial nutrition (food) and hydration (liquids) that aid the body in recovery. As with all medical treatments, this can be helpful or harmful for the patient. Fluids are utilized by the body to keep mucous membranes moist and promote the removal of body waste, while nutrition feeds the physical needs of the body.

When a patient cannot recover from an illness, decisions about artificial nutrition and hydration must be made – difficult decisions. In order to make the best decision possible in relation to each unique situation, it is important to know the facts about artificial nutrition and hydration, and how the body processes foods and fluids:

- Use of artificial nutrition and hydration allows patients to receive nutrition and hydration when they can no longer take enough by mouth to maintain life or health. Doctors can provide this nutrition and hydration through an intravenous line (IV) or by putting a tube in the stomach.
- Artificial nutrition and hydration is different from ordinary eating and drinking. It requires professional skills and training to insert the tube, and know how much and what types of nutrition/hydration to give.
- Because it is given through an IV or tube in the stomach, artificial nutrition does not offer comforts such as taste and texture typically associated with foods and beverages.
- When a patient has a serious illness and can no longer eat or drink, he/she is usually approaching an end of life state where the body is beginning to stop functioning. Even with artificial nutrition and hydration, the patient will not return to a healthy state.
- Many physicians agree that artificial nutrition and hydration can prolong suffering for the patient due to bloating, swelling, cramps, diarrhea, and shortness of breath. It is important to remember that the person's body is beginning to shut down because of the disease and the dying process, and not because of the absence of food and liquid.
- The artificial feeding and hydration cannot bring back the health that was lost due to the advancement of the disease process.
- Legally, artificial nutrition and hydration is a medical treatment and can be refused at any time in the patient's treatment. It is easier for families and/or caregivers to know the patient's wishes if they have completed an advance

healthcare directive that explains the patient's wishes regarding artificial nutrition and hydration.

**A. WHAT TO REPORT TO THE HOSPICE/PALLIATIVE CARE TEAM?**

Tell the team if the patient:

- Is unable to eat or drink
- Has trouble swallowing
- Has a dry mouth or tongue
- Loses more than five pounds in a week
- Is producing less urine
- Becomes confused or drowsy

**B. HOW TO ENCOURAGE PROPER NUTRITION/HYDRATION**

For patients not utilizing artificial nutrition and hydration, there are steps that can help maintain the best possible intake:

- Encourage favorite foods and drinks.
- Offer drinks or sips often - at least every two hours.
- Clean the mouth often - a pleasant tasting mouth may make food taste better.
- Help other family members and friends understand why eating and drinking may cause the patient to be uncomfortable and suffer.
- Support the patient's decision not to eat or drink.
- If dentures do not fit well, consult a dentist.
- Make mealtime a quiet and pleasant time - candles, flowers, soft music and good conversation all help.
- If nausea is a problem, serve small portions of salty (not sweet), dry foods and clear liquids.
- Find other ways besides food and drink to show the patient you care. For example, offer the patient a massage or look through a picture album together.
- Do not force the patient to eat and/or constantly remind him/her about their decreased appetite. The choice of eating is up to the patient.
- Serve meals in a relaxed and comfortable setting and eat with the patient when possible.
- Remove unpleasant odors from the room and avoid unpleasant procedures around meal times.
- Cold foods have minimal odor and are easier to swallow.
- Because of many disease processes, tastes that were once enjoyable may now be unpleasant.

- Allow for rest before and after meals.
- Small, frequent meals are better than three larger meals.
- When regular meals are less desirable, your hospice nurse can make suggestions about high-calorie nutritional supplements.
- As the disease process progresses, food becomes less desirable.
- Appetites tend to decrease throughout the day. Try to make the most of breakfast meals.

### **C. HYDRATION**

1. Fluids are utilized by the body to keep mucous membranes moist and promote the removal of body waste.
2. Do not force liquids; as the disease progresses the patient may experience difficulty swallowing.
3. Encourage intake of high-calorie liquids when possible (such as milkshakes, Ensure).
4. Prune and fruit juices aid in promoting bowel function.
5. Give liquids in other forms such as Jell-O, puddings, ice cream, and popsicles.
6. Very cold or warm liquids are more satisfying than room temperature liquids.

## **IV. FEVER**

### **TIPS FOR DEALING WITH FEVERS**

At times, fever may become a problem for the hospice patient. If so, these options may be helpful:

- Give sponge baths with lukewarm water.
- In conjunction with your physician, your hospice nurse may provide instruction on administering medication to reduce fever.
- Lip balm, tootlettes (little sponges on a stick), or ice chips may be helpful in relieving the dryness of the mouth associated with fever.

## **V. MANAGING NAUSEA AND VOMITING**

### **A. WHAT IS NAUSEA AND VOMITING?**

Nausea is the unpleasant feeling that may occur in the back of the throat or stomach prior to vomiting.

Vomiting is the emptying of stomach contents through the mouth.

### **B. WHAT TO REPORT TO THE HOSPICE/PALLIATIVE CARE TEAM?**

- Amount and frequency of nausea and vomiting.
- Description of vomited fluid.

### **C. WHAT CAN BE DONE?**

The good news is that there is much that the caregiver and the hospice/palliative care team can do for nausea and vomiting. The team will always try to discover the underlying cause and discuss treatments with your healthcare provider, so it would be helpful to have a record of what seems to cause or decrease the patient's nausea and/or vomiting.

Suggestions that may improve patient comfort include:

- Provide sips of carbonated drinks (i.e. 7-Up) that have gone flat.
- Avoid acidic juices (such as cranberry, grape, apple, orange or grapefruit)
- Offer sports drinks (such as Gatorade) - with children use Pedialyte).
- Provide small amounts of salty foods (such as crackers, chicken broth).
- Avoid fried foods, milk products or those with strong smells.
- Provide frequent mouth care (see page 4).
- Provide foods as requested by patient in small frequent amounts as large meals may be overwhelming.
- Avoid strong odors such as perfume and deodorizers.
- Avoid eating immediately after vomiting.
- Offer sips of water or ice chips before eating again.
- Maintain a comfortable room temperature.
- Avoid constipation.
- Administer medications as ordered by healthcare provider.
- Contact hospice/palliative care team if nausea/vomiting continues.

## **VI. PAIN MANAGEMENT**

The fear of pain, the reality of pain and the medications to control pain can produce anxiety for the patient as well as the family. It is important to have FACTS about pain and pain management.

### **A. WHAT IS PAIN?**

The hurting or discomfort a patient experiences can cause physical, emotional, and spiritual suffering. Pain cannot be measured from the outside; pain can only be felt and described by the person with the pain

### **B. WHAT TO REPORT?**

How severe or intense the pain is as a number -- using 0 as no pain and 10 as the worst possible pain imaginable. Additional ways of reporting pain are also available such as faces, thermometer scale - ask your nurse to tell you more about these options. Descriptors helpful for your health care team can be determined with these questions:

- Where is the pain?
- Does the pain keep the patient from doing his/her usual activities?
- What makes the pain worse?
- What makes the pain better?
- How well is the pain medication working?
- Is the patient experiencing side effects of the medication (such as constipation, nausea, vomiting, sleepiness, dizziness, itching).
- What words best describe the pain such as aching, burning, gnawing, grabbing, sharp, dull, continual, etc.
- What is the effect of the pain on the patient and family (for example, is the family anxious or unsure about how to give the medicines? Is the patient becoming irritable from lack of sleep because of the pain?)

### **C. PAIN FACTS**

- The patient is the only one who knows how bad the pain is.
- The patient is the only one who knows how well the pain medication is working.
- Encourage the patient to always be honest in verbalizing how severe the pain is and how often it occurs.
- Remind the patient that pain is not a punishment and does not have to be tolerated.

- An increase in pain does not always mean that the disease is progressing.
- Patients who have had long term pain may not show signs of pain but may still be in pain. Always ask the patient about the pain.
- Reports of pain by the patient should be believed and reported.

#### **D. PAIN MEDICATION**

- Everyone's pain is different. The amount, type, and frequency of pain medication will vary from patient to patient. Do not be afraid of addiction. The patient is taking medication to relieve pain. The patient is not taking the medication for emotional or psychological reasons. Studies have shown patients with pain do NOT become addicted to medication administered within the guidelines.
- It is important to follow the pain medication schedule as instructed by the nurse. This ensures that the patient receives optimal pain control.
- Do not stop pain medication suddenly.
- A patient's pain medication may need to be adjusted periodically. This is a normal process.
- Some long-acting pain medications require up to 24-hours to reach full effectiveness. Your nurse will instruct you on the specific actions of your pain medicine, as well as possible side effects and a dosing schedule. The nurse will visit or call within 24 hours of changing the medication to make sure the patient is comfortable.
- Record pain medications on the pain assessment sheet, as instructed by your nurse. This helps the nurse and physician to evaluate and make necessary adjustments in the pain management plan.

#### **E. PAIN MEDICATION SIDE EFFECTS & HOW TO DEAL WITH THEM**

- Drowsiness or confusion may occur when the patient is increasing a medication or starting a new pain medication. This can lessen in a few days after the body adjusts to the change in medication.
- Remember: the patient may sleep more because the pain is lessened and he/she is more comfortable or he/she may be catching up with a lack of sleep due to pain.
- Some medications can cause mild side effects. Some of these may include:

Constipation- Narcotics dry out the bowel. Your nurse can instruct you on how to establish a bowel routine.

Sweating- This may occur at night. Keep the room cool, have the patient wear light clothing, and cover with a sheet.

Dry mouth- Use of hard candy, cool washcloths, and/or ice chips will help relieve dry mouth and lip balm can be used for chapped lips. Check with your nurse prior to using any of these remedies.

Hallucinations- Some narcotic medications cause hallucinations. Reassure the patient that what they are seeing is not real and that the medication is causing the hallucinations. If your patient becomes anxious, contact the nurse.

Upset stomach- Some medications can be irritating to the stomach. Try to have the patient take the medication with food when possible.

## **F. PAIN CONTROL METHODS**

Pain medications come in many forms: tablet, liquid, suppository, patch, and intravenous. Your nurse will discuss the specifics about pain medications.

- Physical methods that may relieve pain in addition to medications:
  - Heating pad- Check with the nurse before utilizing a heating pad and apply the heating pad for a short period of time only. Always use the lowest heat setting.
  - Ice pack- Place ice in plastic bag, secure opening, wrap in towel, and place on affected area for short periods of time only.
  - Local massage- Apply massage with or without warmth producing lotions such as icy hot or mentholated deep heating rub. Please check with your nurse before providing massage.
  - Soothing music- Ask the patient about his/her preference of music and provide a quiet, comfortable, and soothing environment.
- Other things that might make the pain better are:
  - Relaxing or distracting activities such as watching TV, listening to music or playing a game
  - Smells of certain plants (called aroma therapy)
  - Guided imagery (picturing relaxing scenes to take one's mind off pain)
  - Soaking in a tub of warm water
  - Meditation

The hospice team has specialists to help with relaxation techniques to aid in pain relief as well as psychological pain; please discuss these options with your nurse.

## **G. SLOW RHYTHMIC BREATHING FOR RELAXATION**

Relaxation techniques are easy to learn and they can help to reduce anxiety. No equipment is needed. Rhythmic breathing is free, easy, and effective:

- Breathe in slowly and deeply, then breathe out slowly, feel yourself beginning to relax; feel the tension leaving your body.
- Now breathe in and out slowly and regularly, at whatever rate is comfortable to you. You may wish to try abdominal breathing. (If you are unsure how to do abdominal breathing, ask your nurse for help.)
- To keep focus on breathing slowly and rhythmically, breathe in as you silently say to yourself, "in two, three." Breathe out as you silently say to yourself, "out, two, three." Or you may think to yourself "peace," "relax," or "black velvet" each time you exhale.
- You may imagine yourself in a place that is very calming and relaxing for you, such as lying in the sun at the beach.
- End with a slow, deep breath. As you breathe out, say to yourself "I feel alert and relaxed." Please note that if you intend to do this for more than a few seconds, find a comfortable position in a quiet place. You may want to close your eyes or focus on an object.

## H. PAIN QUESTIONNAIRE

1. Your hospice nurse and physician would like to know your concerns about the pain medications. Put a check mark by any worries you have and your hospice nurse will discuss these concerns with you at his/her next visit.

a. \_\_\_\_\_ I worry that I should save stronger medicines for later.

b. \_\_\_\_\_ I am worried about constipation.

c. \_\_\_\_\_ I am worried about increased drowsiness.

d. \_\_\_\_\_ I worry about stomach upset.

e. \_\_\_\_\_ I do not like to complain about pain.

f. \_\_\_\_\_ I am worried about addiction.

2. What other worries do you have concerning pain and pain medications?

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## **VII. MANAGING FATIGUE**

### **What is fatigue?**

Fatigue feels like tiredness, exhaustion or lack of energy. It is a condition which impacts the ability to perform any activity - and it's seen frequently in hospice and palliative care patients. Fatigue is a complicated symptom which can have many causes and sometimes comes with depressed feelings

### **What are the signs that a patient is fatigued?**

- Unable to perform the normal activities for that patient - every person is different in their normal activity level, "just too tired"
- Not participating in the normal routine
- Lack of appetite - do not have the energy to eat
- Sleepiness
- Not talking
- Depressed

### **What should be reported to the Hospice/Palliative Care Team?**

- Share signs of any of the behaviors listed above
- What seems to make the fatigue better or worse?
- Any distressing symptoms that are not controlled
- Any concerns you as the caregiver have about the fatigue
- Spiritual concerns voiced by the patient
- Assist your loved one to rank their fatigue using a scale - it helps the team to be able to find what works for him/her and how severe the fatigue is:  
0 = no fatigue                      10= in bed all day

### **What can be done to help fatigue?**

Because fatigue is a complex problem, it takes a group of actions to help the symptoms. The team will work with the patient, family and the primary care provider to find the causes for the fatigue and discuss treatments.

#### **Things family can do:**

- Plan, schedule and prioritize activities at optimal times of the day; help the patient keep a log of which time of the day seems to be best
- Eliminate or postpone activities that are not his/her priority
- Assist with position changes to help with physical body stress
- Use sunlight source to cue his/her body to feel energized.
- Assist with daily activities such as eating, moving or bathing to conserve energy
- Plan activities ahead of time
- Accept the new energy pace of the patient

- Rest and sleep better:
  - Encourage him/her to rest as needed
  - Establish and maintain a regular bedtime and awakening time
  - Avoid sleeping later in the day, which could interrupt nighttime sleep.
  - Plan rest times or naps during late morning and mid afternoon
  - Ask the team if using oxygen while sleeping will help.
- Increase and improve food intake:
  - Try nutritious, high protein, nutrient dense food
  - Small frequent meals
  - Add protein supplements to foods or drinks
  - Frequent mouth care (before and after meals)
  - Ask your team about possible use of medications to stimulate appetite

## **VIII. MANAGING RESTLESSNESS**

### **What is restlessness?**

Restlessness is an inability to rest, relax, or concentrate; extreme restlessness is sometimes called agitation. Many patients experience restlessness, and nearly half of all patients during the last 48 hours of life

### **What are signs that the patient is restless?**

Restlessness is generally easily identified and can include muscle twitching, fidgeting, moving around without a known reason, plucking/pulling at sheets, covers or clothing, trying to get out of bed for no apparent reason, sleeplessness, an inability to get comfortable, and grimacing.

### **What can be done to make the patient more comfortable?**

The team will try to find the reason for the restlessness and talk with you about helpful treatments. There are some options you can use including:

- Give medications to the patient as ordered
- Offer frequent reassurance to the patient and remain quietly nearby as much as possible
- Offer relaxation activities if the patient is alert and oriented
- Play soothing music and keep things calm around the patient (for example, decrease number of visitors)
- Read favorite stories, poems, etc. in a calm voice
- Do gentle massage, comforting touches, or other things to calm the patient
- Keep the patient safe (do not leave the restless patient alone)
- Understand that restlessness may be a sign that the patient is close to death - let other family members know what is happening

### **What to report to the Hospice/Palliative Care Team?**

- Any of the signs or behaviors of the patient listed above
- Inability of the person to swallow medications
- Things that make the restlessness worse (for example – loud music) and things that make the restlessness better (for example – soft music)
- Concerns that you may have as caregiver - what will help you cope with the restlessness
- Emotional or spiritual concerns
- Situations that might be unsafe (for example, the need for side rails to keep the patient in bed)

## **IX. MANAGING ANXIETY/UNEASY FEELINGS**

### **What is anxiety?**

Anxiety is the feeling or deep sense that things are not right.

### **What are the symptoms of anxiety?**

A person experiencing anxiety may exhibit fear, worrying, sleeplessness, confusion, rapid breathing, shaking, sweating, an inability to relax, or difficulty

### **What can be done?**

The team will try to find the cause for the anxiety and discuss treatments with you and your primary care provider. Steps you can take to alleviate some of the patient's anxiety are to keep things calm, treat physical problems such as pain, play soothing music, speak quietly to the patient, provide medications as prescribed, or massage the patient's arms, hands, feet or back.

### **What to report to the Hospice and Palliative Care Team?**

Be sure to share any fears or worries the patient voices such as fear of dying, money worries, relationship problems with family or friends, or spiritual concerns. Keep the team informed of any signs that the anxiety is getting worse.

## **X. MANAGING DELIRIUM**

### **What is delirium?**

Delirium is the sudden change in a person's mental status over a period of hours to days that results in mental clouding with less awareness of one's environment and confusion about time, place, and person.

### **What are the signs and symptoms of delirium?**

Delirium shows in various ways including the reversal of sleep and awake cycles, "Sundowning" or confusion that worsens at night, mood swings, difficulty focusing attention, hallucinations, agitation and irritability or drowsiness and sluggishness.

### **What can be done for delirium?**

**Delirium can be caused by many things and is common at the end-of-life.** The team will try to find out what is causing the delirium and discuss treatment options with you. As a caregiver you can:

- Keep the patient safe
- Remind the patient of who you are and explain what you are going to do. For example, "I am going to help you get out of bed now."
- Offer reassurance and support such as "I am right here with you."
- Try to maintain a routine and structure
- Avoid asking a lot of questions
- Provide a quiet, peaceful setting, without TV and loud noises
- Play the patient's favorite music
- Keep a nightlight on at night
- If starting a new medication, watch for improvement, worsening, or side effects and report to healthcare provider

### **What to report?**

Be sure the Hospice/Palliative Care team members are aware if any of the signs or behaviors listed above occur as well as changes in food or fluid intake, decrease in urine output, or change in frequency or type of bowel movements. Other symptoms that may be pertinent are depression, wandering, and withdrawal from people or activities formerly enjoyed. The nurse needs to know of all changes in medications.

## **XI. MANAGING DEPRESSION**

### **What is depression?**

Depression includes a range of feelings: sadness, gloom, numbness, emptiness, helplessness and hopelessness. Chronic and terminal illnesses often induce depression, and it is sometimes difficult to determine if the symptoms seen are a result of the illness or depression.

### **What are the signs and symptoms of depression?**

- Fatigue
- Sadness, depressed mood
- Loss of appetite with weight loss
- No interest or pleasure in daily activities
- Withdrawal from family and friends
- Sleep problems
- Feelings of worthlessness, hopelessness, guilt
- Difficulty focusing and thinking
- Thoughts of death or suicide
- Agitation or slowing down

### **What can be done for depression?**

Depression is common at the end-of-life and displays a wide range of intensity. The home health team will help you sort out causes of depression and discuss treatment options with you. Some steps you can take might include:

- Help optimize the patient's physical status with rest and nutrition
- Set small, realistic, achievable goals to help the patient's sense of well being
- Encourage the use of relaxation techniques and consider complementary therapies such as aromatherapy, art and music therapy
- Take caution to keep the patient and area safe
- Remind the patient that you will be there to help
- Allow the patient to express feelings without discounting them
- Give the patient as much control as possible in activity and treatment decisions

### **What to report to the Hospice/Palliative Care Team?**

- Tell the nurse about any of the above symptoms as well as any known history of depression
- Make a note of physical symptoms such as pain, nausea, difficulty breathing
- Report changes in medications the team may be unaware of

## **XII. SOCIAL DISTRESS**

### **A. What is social distress?**

Social distress is a disruption in one's social life (changes in roles, relationships, sense of belonging, sexual function, and appearance) that causes a suffering of mind or body

### **B. What are the signs and symptoms of social distress?**

Patients experiencing social distress may talk about feeling lonely and/or feeling alone, or being a physical or financial burden to others. It will become apparent that they are unable to carry out personal roles (spouse/partner/parent/friend, etc), and may feel shame for that failure. Those in this situation often do not want company or visitors, even close friends or relatives whom they have always treasured.

### **C. What to share with the Hospice Team?**

- Any signs of behaviors listed above
- Any expressions of suicide
- Prior history of social distress
- Unusual anger or lashing out; the patient may not understand reason for anger or how to cope and may take it out on others
- Any change in relationships that concern you

### **D. What can be done for social distress?**

Social distress is common with terminal illnesses and not every patient experiences it the same way or to the same degree. Never feel that you are bothering the team with questions. Asking questions means you care.

Other ways to demonstrate your care is to provide a calm setting, be willing to be present without 'doing' anything, treat the patient with dignity and respect, and be willing to listen.

You may be able to help the patient cope by reminding the patient that:

- It is okay not feel up to talking with many people but that it is very important to have at least one person to trust – someone to share thoughts and feelings
- It is okay to be angry and to tell others about your anger
- It is important to take medications for pain and other symptoms
- It is okay to want quiet time
- It is okay to use this time to reflect, record memories, and create future messages for family and friends

### **XIII. SPIRITUAL DISTRESS**

**A. What is spiritual distress?**

Spiritual distress is a disruption in one's beliefs or value system which affects a person's entire being. It shakes the basic beliefs of one's life.

**B. What are the signs and symptoms of spiritual distress?**

- Questions the meaning of life and own belief system
- Afraid to fall asleep at night or other fears
- Angry at God/higher power
- Experiences a sense of emptiness; loss of direction
- Seeks spiritual help
- Questions the meaning of suffering
- Pain and other physical symptoms can be expressions of spiritual distress, as well

**C. What to report to the Hospice/Palliative Care Team?**

- Any signs of behaviors listed above including behaviors that are out of character for the patient at this time, not caring about self and life in general, or the sudden rejection or neglect of previous practices or beliefs
- Side effects of medications
- Any symptoms that are getting worse
- Talking about suicide
- Known history of spiritual distress

**D. What can be done for spiritual distress?**

Spiritual distress is common with terminal illnesses although not everyone experiences it, or feels it the same way or to the same degree.

- Look for ways to keep and honor desired rituals and ways of life.
- Provide a calm, relaxing setting.
- Be willing to be present without having to "do" something.
- Treat the patient with dignity and respect.
- As much as you can, enjoy time together and look for ways to make memories.
- Do not say, "I know how you feel" because you do not. Instead, offer empathy for the continual loss of familiar meaning.
- Support any desire to maintain links with friends and family.
- Be willing to listen and reminisce.
- Be open to giving spiritual support if asked or contact your minister, rabbi, priest, etc.

- Recognize that family/friends/caregivers can experience spiritual distress as well.
- Encourage the patient to have at least one person to trust and talk with about fears and concerns.
- Allow the patient to be angry.
- Offer the opportunity to hear devotional tapes or soothing music.
- Try listening to music without words.
- Ask the patient if someone else can pray for them, if the patient is unable.
- Encourage the patient to take prescribed medication.

## **XIV. DEMENTIA**

### **A. What is dementia?**

Dementia includes multiple cognitive deficits that progress gradually over time. The most common deficit is memory impairment that can affect the ability to interact with others or function independently. Alzheimer's Disease is one kind of dementia.

### **B. What are the signs and symptoms of dementia?**

People with dementia may consistently demonstrate some of these issues: Forgetfulness, difficulties with familiar activities, or math and language problems. Patients may not be able to use simple words that have long been part of their vocabulary. They may lose their sense of direction, going somewhere familiar and not knowing how to get back home. They may demonstrate poor judgment by dressing inappropriately to the weather or occasion. They may put things in the wrong place, such as the milk in the bathroom. Sudden mood swings may come on, or you may see a personality change drastically over a period of time. They may lose interest in hobbies and people they love.

### **C. What to report to the Hospice/Palliative Care Team.**

It is important for the health care team to know about any signs of behaviors listed above or any attempts by the patient to hurt him/herself or others.

### **D. What can be done for dementia?**

To offer support to someone with dementia:

- Treat the patient with respect.
- Remember to treat an adult as an adult, not like a child which could be embarrassing. Offer explanation before helping patient with care. Try to understand the emotions and feelings of the patient, who may feel confused, frightened and threatened. Remember that you cannot understand everything; you can only do your best.
- Set limits and take control when possible. You may need to remind the patient of the day, place and time
- Create a daily routine with small rituals. These can include prayers, washing hands, or preparing food. Try not to do too little or too much.
- Allow the patient to do as much of their own care as possible. This will help maintain their self-esteem
- Include former habits and memories. Provide the patient with things to hold that represents a part of his/her life including pictures, clothing, or other objects with meaning to the patient

- Provide physical closeness with touching, gestures and eye contact. Show your own feelings.
- Do not expect the patient to remember. It can bring on anxiety and feelings of failure. Your loved one may be losing memory, but the senses never “forget”. Try stimulating their senses through aromatherapy, pleasant sounds, music from their era, tactile pieces, or visually with a mobile or lava lamp.
- Talk in a calm and reassuring manner.
- You may need to be more tolerant of unusual behavior by reducing your reaction to bizarre behaviors. Resist the impulse to control the patient’s behavior because the behaviors may have meaning for the patient which makes no sense to you. Try to move calmly to a new activity when the patient becomes stressed.

Caring for someone with dementia is very demanding. Take care of yourself. If you begin to feel overwhelmed, realize that the sooner you accept help, the longer you can help the patient. Always be aware of safety.

## **XVI. EMOTIONAL WITHDRAWAL**

Individuals with terminal illness often withdraw from familiar activities and from their loved ones. Withdrawal is often used to conserve energy and to allow the patient time for self-reflection, and touch and silently being with the patient may become more meaningful. Talk with Hospice staff about your questions and concerns regarding your loved one's emotional withdrawal – they can help in this life reflection process with patients and their loved ones.

### **Disorientation**

In the weeks prior to death, the patient may begin to sleep much of the time. It may become difficult to keep their eyes open, and they may become disoriented to time and place. The patient may be confused or may talk or gesture to people who are not present or those who have already died. Patients may often speak in what is called Symbolic Language, which includes statements such as, "I have to pack for my trip" or "I have to cross the bridge now." These activities are normal and can be reassuring and calming for the patient. If you have questions or concerns talk with the Hospice staff.

### **Caregivers**

You can offer support at this important end of life time. Letting go is one of the most powerful expressions of faith and the greatest parting gift you can offer your dying loved one. Saying goodbye can be painful, but it is more so if you believe the illusion that after you say goodbye your loved one will die. The act of saying goodbye will sometimes be repeated over and over in different forms. Hearing the words – having your blessing – creates a foundation of trust so that your loved one can feel secure in letting go. Helping your loved one move from your hands to the next world might include the following:

- Touch your loved one; hold hands, rub the head.
- Tell your loved one you love him/her, and if the patient is unable to respond answer yourself "And I believe you love me, too."
- Forgive your loved one of any past estrangement/behaviors/words. If they are unable to respond answer: "And I believe you forgive me, too."
- Tell your loved one about your shared beliefs in spirituality.
- Share with your loved one your favorite memories with him/her, and why he/she is important to you. This is a wonderful time to express gratitude you may feel toward the patient.
- Give your loved one permission to let go.

## **XVII. USING OXYGEN SAFELY**

**If the patient experiences difficulty breathing, try the following:**

1. Raise the patient's head with pillows or raise the head of the bed.
2. Use oxygen if ordered.
3. Give pain medications or sedation as ordered.
4. Stay with the patient if possible (having trouble breathing is scary).
5. Turn a fan on in the room to provide better air circulation.

### **B. OXYGEN THERAPY**

#### **Using Oxygen Safely**

Oxygen is a drug and must be used only as prescribed by the physician. Treat it just like any other medication, and do not change the amount unless instructed to do so. The oxygen supply company will provide the proper instructions regarding the use of oxygen. Here are a few basic tips:

- The prongs of the nasal cannula must be in the patient's nose. If using a facemask, it must fit snugly on the face. Make sure the nasal cannula or facemask is clean to reduce potential infection and to ensure adequate oxygen delivery.
- Small pieces of cotton or pads between tubing and skin can lessen irritation.
- Be sure you understand how to use the equipment and any backup system.
- Never use petroleum products (e.g. oil or grease) if oxygen equipment is being used because of the risk of a fire. Vaseline is a petroleum-based product and should never be used for nasal irritation. Instead, use a water-based moisturizer such as K-Y Jelly.
- Oxygen tubing should be no longer than 50 feet, because longer tubing can decrease the amount of oxygen received by the patient.
- Those smoking cigarettes, cigars or pipes should not be in the same house/room as oxygen.
- Keep open flames (candle, wood stove, pilot light for stove, and fireplace) at least 10 feet away from the person using oxygen, all tubing, and the source of oxygen.

#### **Oxygen can be provided in different ways:**

Concentrators are machines that take the air and concentrate it into oxygen. These should be kept away from curtains, heating units or open flame. Remove any frayed electrical wiring, and do not use extension cords with concentrators because they can overload

circuits. Do not use aerosol sprays near the concentrator because they can clog the filter.

Liquid Systems must be stored in a cool, well-ventilated place at least 10 feet from outlets, open flames, or heat sources. Do not touch the fill adapter (the area that frosts over) after filling the portable. When traveling with liquid oxygen, follow the special precautions. During hot weather, car temperatures may exceed 200° F, so leave windows open for ventilation. Be sure the car's electrical system is in good working order to prevent sparks from igniting in a highly combustible atmosphere.

Tank/Cylinder Oxygen must be stored away from heat sources, because the pressure inside the tank increases for each 5-degree increase in cylinder temperature. Because of high pressures inside the tank, damage to the tank or regulator can be dangerous. Do not store in hot, unventilated areas such as trunks of cars, closets, or storage units. Extra oxygen tanks should be stored by laying flat on floor or in a secure tank holder.

***Note: Both liquid and cylinder oxygen must be secured with a seat belt when traveling. Your oxygen supply company will also provide you with all instructions and education needed.***

**Do not smoke or allow others to smoke in the presence of oxygen. It is a dangerous fire hazard. Store tanks standing upright and secured with good air circulation.**

## C. SUCTIONING

Often as patients become weaker, they are unable to cough deeply enough to bring up secretions which may collect in the throat and mouth, and suctioning may be needed. The items necessary are: (1) Suction machine (2) Suction catheters (3) Container of clean water. The nurse will teach you how to use the equipment, but these reminders may be helpful:

- Check to be sure the machine is plugged in, then turn it on.
- Place the catheter tip in the clean water and suction a small amount of water.
- Place catheter in mouth, moving from side to side within the mouth and over the tongue.
- Be careful to avoid putting the catheter too far in the back of the throat, which might cause gagging.

- Put catheter tip in water and clear tube.
- Ask the hospice nurse if the catheter can be reused.

#### **D. SHORTNESS OF BREATH**

Some patients experience a feeling of breathlessness at the end stages of life, and may experience an uncomfortable feeling of having difficulty breathing. Sometimes it is described as not getting enough air (feeling that he/she cannot get their breath), feeling like the room is closing in, or there is not having enough air in the room,

##### **What to report to the Hospice/Palliative Care Team?**

Let the health care team know when the patient demonstrates fear, anxiety, nervousness or restlessness. Contact the team if there is a bluish discoloration of face, nose, fingers, toes.

##### **What can be done to help the patient?**

- Make notes about what seems to increase shortness of breath and what decreases it.
- Increase air movement by using an open window or fan.
- Keep room cool and apply cool cloths to face, neck and/or chest; if air conditioner is not available, try sitting a bowl of ice in front of a fan.
- Keep the environment quiet to decrease feelings of anxiety.
- Elevate the patient's head or sit the patient in chair or recliner.
- Use relaxation techniques with spiritual support, yoga, calming music, massage.
- Focus on breathing - encourage slow, deep breaths or use breathing exercises.
- Use pursed lipped breathing (breathe in through the nose and blow air out through the mouth slowly with lips pursed together)
- Use oxygen as directed by the healthcare team.
- Provide medication as directed by the physician.

## **XVIII. THE END OF LIFE**

Talking about death is not easy for many people. Those who know that life's end is near often reflect on their experience – and it does not have to be a lonely, difficult task. If you are comfortable, you may wish to explore some of these topics; you may find some wonderful avenues open for you to help your loved one in a deeply personal manner.

### **Questions About Living for the Patient**

When there is only a short time left in life, choices must be made:

- What do you still want to accomplish?
- What do you need to do to ensure your affairs are in order?
- Who are the people you want to spend time with?
- Are there issues to resolve or conversations to have?
- What will bring pleasure to this part of your life?

It is healthy to think about these questions and to talk about them with family and friends. Knowing life's end is drawing near can allow patients to focus their energy on the people and issues important to them.

### **Questions About Dying for the Patient**

It is natural to have questions about death. It is mysterious, and we all wonder about the process and what it means.

- What do I believe about death and what happens to a person during and after death?
- What can help me with my feelings of fear and sadness?
- What can I do to make peace with the person I have been and who I am now?
- What kind of service or other remembrance do I want after my death?
- Whom do I want with me when I die?

While these questions can be painful, they can also bring inner peace. Those experiencing a terminal illness need others who will encourage them to explore these questions, and who will listen and offer support.

### **Where To Go For Help**

There are many individuals who can help patients and their families when the end of life is near, sometimes just to talk and gain spiritual comfort, or maybe to help resolve a family conflict or other issue. Don't be afraid to ask for help from:

- Hospice staff
- Priests, ministers, rabbis, or other spiritual leaders
- Private therapists

- Support groups
- Friends and family

### **Preparing for Death**

When a friend or family member is dying, the patient needs to know that you are open to talking or listening when the time is right. Do not be afraid to laugh or to cry. Emotions can bring healing – for the patient and for the caregiver. Be willing to change your plans or your topic of conversation based on how your loved one is feeling. Let the patient know what you treasure about him or her and why they are important to you.

In the final stages of the dying process, the body begins to shut down, and the individual begins to release himself emotionally and spiritually. The Hospice team is here to help you through this process, so use them as a resource.

## **XIX. FINAL DAYS**

### **What are the signs and symptoms that the patient is close to death?**

As death nears, the patient may:

- Sleep more, withdraw from people or have little to say
- Speak to people not present
- Talk about leaving or taking a trip or journey
- Eat or drink less and have trouble swallowing
- Become more confused
- Make moaning sounds
- Lose control of urination and bowel movements
- Have moist breathing or sound congested
- Have changes in the pattern of breathing such as long periods without breathing followed by several quick, deep breaths
- Have blurred vision and/or not hear as well as usual
- Have less pain
- Have cool feeling hands and arms or feet and legs
- Turn blue around nose, mouth, fingers, and toes

### **What should you report to the hospice team?**

Changes in the patient such as

- Restlessness or anxiety
- Changes in breathing
- Pain or discomfort
- Need for spiritual, emotional, or social support or guidance for the patient or family. Concerns that may need help from the social worker, chaplain or other members of the hospice team.
- Religious, cultural, or ethnic traditions important to your family.

### **What can be done for the patient?**

- Allow the patient to sleep without guilt or chiding.
- Continue to sit with your loved one, speaking softly and naturally. Speak to your loved one directly as you normally would – never assume the person cannot hear. Do not talk about this person in his or her presence. Hearing is the last of the senses to be lost.
- The person may seem confused about the time, place, and identity of those present. Speak softly, clearly and truthfully when you need to communicate something important, such as saying that it is time to take medication to reduce the pain.
- Turn the patient if it makes him or her more comfortable. Elevating the head or turning the person onto the side may bring comfort.
- If congested, gently turn the head to the side, allowing gravity to drain the secretions.

- Moisten the patient's mouth with a moist washcloth or cotton ball. Ice chips or frozen juice may refresh the mouth, or you can give small amounts by dropper or straw, if the person can swallow (ask hospice nurse).
- If the patient has a fever or is hot, apply a cool rag to the forehead
- Give medications ordered by the doctor to decrease anxiety, restlessness, agitation, or moist breathing
- Use light massage on the forehead, read to the person, or play soothing music to relieve restlessness.
- Write down what the patient says. Such messages may comfort you later.
- Continue to talk clearly to the patient and say the things you need or want to say. Remember that the patient may be able to hear even when unable to respond.
- Keep a light on in the room. The patient cannot see well and may be frightened by darkness and shadows.
- Play the patient's favorite music softly
- Encourage visitors to talk directly to the patient and tell the patient who they are.
- Keep things calm around the patient.
- Open a window or use a fan in the room if the patient is having trouble breathing.
- Continue to touch and stay close to reassure your loved one.

## **XX. WHEN DEATH OCCURS**

Everyone handles the time of death in different ways. The Hospice team can help prepare you so you know what to expect. An expected death is not an emergency, so you can spend some precious time with your loved one.

### **Signs of death:**

- No breathing
- No heartbeat
- No response to communication
- Eyes fixed on a certain spot
- Eyelids slightly open
- Jaw relaxed and mouth slightly open

### **When you want the support or when the patient dies:**

- Call the Hospice office. A team member will speak with you and come to your home.
- It may be helpful to have a friend or family member come be with you.
- If you wish, the nurse will call the funeral home for you after the death. The funeral home usually arrives within an hour after the call. You may choose to wait to call the funeral home until other family members or friends arrive.

At the time of death, the hospice team will need to know:

- Name of the funeral home you want to use
- Whether the body will be embalmed or cremated
- Names of family members to be contacted

## **XXI. WORKING WITH A FUNERAL HOME**

When a person dies, those left behind must deal with many issues of grief and loss. At the same time, a number of practical and business decisions must be made. One pressing issue is making funeral arrangements. You should be in contact with the funeral home within 24 hours of your loved one's death to set up an appointment with a funeral director.

Making funeral arrangements for oneself or someone else can be a difficult and emotionally painful process. It can seem overwhelmingly complicated. Where do you start? How do you find a funeral home? How do you know which funeral home is the best for your needs? When should you call and begin to make arrangements?

### **Planning Ahead**

People often avoid the subject of funeral planning until there is a death. Often, waiting increases the difficulty of making clear and consistent decisions; even with pre-planning, there will be many choices and decisions to be made. The more that can be started and completed ahead of time, the more opportunity there will be to focus on the feelings and emotions that surround a death. Talking about preferences and plans with others may seem difficult but it is the best way to know the patient's wishes.

### **Making Decisions**

Most funeral directors are professionally trained, providing services with compassion and integrity. They play an important and necessary role in the community, working with people at an especially vulnerable time. When someone you love has died, you need to make quick decisions on painful issues, such as burial or cremation, what kind of casket to buy, where to purchase a burial plot, and what kind of service to have. Some decisions may involve significant amounts of money as well as emotionally charged, so they become more complicated. Here are some suggestions to help minimize the risk of making decisions that you may later regret.

- Never send one family member alone to make funeral arrangements. If possible, have two or three family representatives go together, including one who is more detached from the pain of loss than a spouse or child.
- Most funeral homes offer a basic minimum service package, beyond which additional services are charged individually. Make sure that you understand what is included in the basic service and what is extra.
- If you have questions about whether you want or need some of the services offered, go home and think about it, then call back with your answer.

### **Services Performed by the Funeral Home**

- Immediate services including staff counseling, administrative direction, preparation, and embalming of the body for burial.
- Facilities and equipment including the use of the preparation room and equipment, use of room where body lies for visitation and a funeral or memorial service.
- Assist with preparation of the obituary, and will complete necessary paperwork for the death certificate, and needed copies.
- Caskets will be available at a range of costs.
- Basic transportation including transfer of the body from place of death to funeral home, and a hearse for local service.
- Cemetery including cost of plot, cost of opening and closing the grave, cost of a vault, and headstone. Cemeteries usually do not open graves over the weekends and will charge an extra fee for Saturday burials.
- Optional/additional costs - will include limousines, drivers, police escorts, service folders, and gratuities. Generally, gratuities are given to the minister, organist, soloist, custodian, and to the church group that serves refreshments after the funeral.
- Cremation services includes the cost of cremation, and if ashes are buried, additional costs.
- Bequeathal of body - includes fee the medical school charges for accepting a body and transportation of the body.

### **Planning a Funeral or Memorial Service**

The funeral or memorial can be a simple or a more formal service. Either can be comforting as you share time with family and friends to laugh, cry, and remember together. See Appendix D - Planning a Funeral or Memorial Service

## Appendix D

### PLANNING A FUNERAL OR MEMORIAL SERVICE

Page 1 of 2

- A. Name: \_\_\_\_\_
- B. Type of Service (check all that apply):  
 Funeral - open casket  
 Funeral - closed casket  
 Memorial Service  
 Religious  
 Non-religious  
 Family Only  
 Open  
 Other
- C. Location of Service: \_\_\_\_\_
- D. Date of Service: \_\_\_\_\_
- E. Time of Service: \_\_\_\_\_
- F. Will there be visiting hours before the service?  Yes  No
- G. If *Yes*, where will visitation be held? \_\_\_\_\_
- H. When? \_\_\_\_\_
- I. Will there be a reception after the service?  Yes  No
- J. If *Yes*, where? \_\_\_\_\_
- K. When? \_\_\_\_\_

L. Service Arrangements (check all that apply)

- 1 Organ or other instrumental music
- 2 Soloist
- 3 Choir
- 4 Hymns for congregation to sing
- 5 Musical selections
- 6 Scripture or other readings
- 7 Eulogies

M. Other details: \_\_\_\_\_

N. Participants:

Officiant (priest, rabbi, pastor, other) \_\_\_\_\_

Musicians: \_\_\_\_\_

Speaker(s): \_\_\_\_\_

Pallbearers/honorary pallbearers: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Ushers: \_\_\_\_\_

O. Other notes: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

## **XXII. GRIEF AND MOURNING**

### **What is grief?**

Grief is the normal, emotional response to a loss, and each person grieves in his or her own way. There is no right way to grieve. There is no specific timetable for completing the grief process. While grief is often associated with the death of a loved one, it may also be experienced at the time of other losses such as the loss of function due to illness, loss of a pet, losses such as divorce, the loss of future dreams, role changes and many other changes in life or health. Terminally ill people experience grief as their illnesses progress and their lives are diminished.

### **What is mourning?**

Mourning is the outward expression of grief and includes rituals and customs such as funerals, viewing of the body, cremation and other customs. Each religion, culture, ethnicity, and even different parts of the same country may have different expressions of mourning.

### **What may be expected during the grief process?**

Although we all grieve differently, grief affects behavior, emotions, mental and physical well being.

Among the physical experiences are such things as:

- Tightness in the chest and throat, breathlessness
- Headaches and dizziness
- Exhaustion or weakness
- Dry mouth
- Muscle aches

Among the thoughts that one has, you may find:

- Disbelief and shock
- Confusion and difficulty concentrating
- Hallucinations
- Preoccupation with the deceased

Some of the emotions that are most often felt include:

- Sadness, helplessness, or yearning
- Anger, which may be directed at God, family, health care providers or the person who died
- Shock, guilt and anxiety
- Numbness or ambivalence
- Shame
- Fear

**Changes in behavior may include:**

- Sleeping more or less
- Eating more or less
- Withdrawal from usual activities
- Crying
- Over activity/keeping busy and distracted
- Dreams of the deceased

**What can be done to help one heal?**

- Give yourself permission to grieve.
- Get plenty of rest and exercise, and eat a healthy diet.
- Try to have at least one person with whom you can share your feelings and from whom you will receive support.
- Consider keeping a journal to write down your feelings.
- Do not push yourself to make changes in your life too quickly.
- Reminisce and put together a memory book.
- Attend a community grief support group.

**How to help children cope with grief?**

- Children will experience grief in cycles. As they develop, they will understand more about their grief. Children may ask the same questions repeatedly. Giving them the same answers each time provides them with a sense of stability and trust.
- Adults must be careful when talking with children about death. Using words that are “softer” to describe death may actually cause more confusion. To describe someone who has died as being “lost” or “sleeping,” may cause the child to think that the loved one is coming back or to fear sleeping.
- Children need honest information about their loved one’s illness at a level they can understand. Talk to them about the person’s health condition and the signs that death is approaching. Expressing your own feelings during these discussions may help children express theirs. The Hospice Team can provide information how to help children cope.

**When should you ask for help?**

Your hospice or palliative care team will give you support beyond the death of your loved one. Please use them as a resource if you experience:

- Persistent intense grief reactions months after the loss (not just occasional intense grief reactions)
- Thoughts of suicide or self-harm
- Social isolation
- Unplanned changes in weight
- Increase in use of alcohol or drugs

## **XXIII. OTHER BUSINESS MATTERS**

In addition to a funeral or memorial service, you may also need to follow-up on other tasks following your loved one's death, such as:

### Personal Business:

- Contact your loved one's lawyer about a will or any other legal business.
- Contact the bank, financial planner, accountant, insurance contacts, and others who may need to be notified. Many of these contacts will need copies of the death certificate in order to pay benefits or transfer them to surviving family members.
- Cancel subscriptions and club memberships, and stop or forward mail delivery.
- Address any unpaid bills; contact credit card companies.
- Sort through and dispose of your loved one's personal belongings; this may be easier if shared with other family members.

### Social Security Benefits:

You will want to contact the Social Security Administration regarding the death. If you apply for either of their benefit programs, medical and other information will be collected from you and a decision will be made as to whether or not you meet Social Security's definition of disability.

*Social Security Disability Insurance* – this pays benefits to you and certain members of your family if you are “insured”, meaning that you worked long enough and paid Social Security taxes

*Supplemental Security Income* – this pays benefits based on financial need

### Survivor Benefits

A family member or other responsible person for the beneficiary's affairs should do the following upon death:

- Notify Social Security of the beneficiary's death by calling the Social Security Administration at 1-800-772-1213.
- If monthly benefits were being paid via direct deposit, notify the bank of the death. Request that any funds received for the month of death and later be returned to Social Security as soon as possible
- If benefits were being paid by check, do not cash any checks received for the month in which the beneficiary died or thereafter. Return them to Social Security as soon as possible
- It may take weeks or even months to handle your loved one's affairs, and it can be tiring and emotional work. You do not need to take on everything at once. Be sure to share the responsibilities with other family members.

## **XXIV. HOSPICE CHECKLIST FOR LEGAL AFFAIRS**

- A. The purpose of this section is to guide families in thinking about what is necessary for legal affairs to be concluded after a loved one's death.
- B. This is not to be used in lieu of legal advice and is not meant to be legal advice. As always, the advice of your attorney is of paramount importance.
- C. Estate Planning

- 1 If estate planning is in place, it is always advisable to contact the attorney and inform him/her about the patient's health status. That allows the attorney to check the file to be sure it is up to date, reflecting any changes in the law, which have occurred since executing the documents. At that time, updating amendments to the documents can insure that the patient has the most current document.
- 2 If no estate planning were in place, it would be good to contact an estate-planning attorney to help implement documents that will help in transition. This would include but not be limited to:
  - a. Health care directive, which names an agent to make medical decisions if necessary, and includes up to date HIPPA provisions.
  - b. Durable Power of Attorney(s), which name an agent for financial matters.
  - c. Will
  - d. Living Trust to avoid probate and provide for secrecy of trust provisions.
  - e. Documents titling assets in the name of the Living Trust if one is created.

### **D. Documents Needed in the Event of Death**

Gathering documents needed with the help of the patient will simplify the tasks of the family after death. This is a suggested list of what might be needed.

- 1 Original Will: The latest Will that has been executed will be needed. Usually only one original Will is executed.
- 2 Living Trust and Amendments. There are normally several trusts executed. An executed Trust and any subsequent amendments to that trust are needed.
- 3 Account Statements: The latest monthly statements of assets are needed. They might include:

- a. Brokerage statements
  - b. Bank statements
  - c. Annuity statements
  - d. Mutual fund statements
- 4 Security Certificates for stocks and/or bonds
  - 5 Certificates of Deposit
  - 6 Deeds to real estate
  - 7 Vehicle Titles including autos, boats, trailers, boat motors, RVs.
  - 8 Life Insurance policies
  - 9 Income Tax Returns for last three years if possible.
  - 10 Prenuptial Agreement if any.
  - 11 Military Discharge Papers if any.
  - 12 Personal Effects Letter detailing items to be distributed to people after death; it must be signed and dated by the patient to be binding.
  - 13 Death Certificate of a deceased joint owner on an asset. If no certificate can be found, a new one can be obtained from the Bureau of Vital Statistics of the county of the deceased person's residence.

E. Titling of Assets:

- 1 If stocks and bonds are held in safekeeping at a brokerage, it simplifies dealing with the securities.
- 2 Any assets titled in a deceased person's name alone will need to be processed through the Probate Court.
- 3 Consider titling all assets in a Living Trust, which will ease the transfer of assets after death and avoid Probate Court.
- 4 Sometimes joint ownership is appropriate and sometimes it is not. Please consult your attorney for advice on this point.
- 5 On vehicles, if the title is issued in Missouri, consider using a "TOD" (Transfer on Death) registration, naming a beneficiary of the vehicle. This can be accomplished at a Department of Revenue office. The patient's signature will be required.
- 6 Check all beneficiary designations to be sure they are consistent with your estate planning. Consult with your attorney about what the designation should be.

F. Information Needed:

There is information needed which would be helpful to gather with the help of the patient which will ease the transition after death. The following is a suggestion of the type of information that may be needed.

- 1 Patient Information:
  - a. Social Security Number
  - b. Date of birth
  - c. Year patient moved to Missouri or Illinois
  - d. Occupation (even if retired)
  - e. Father's name
  - f. Mother's maiden name
  
- 2 Deceased Spouse Information:
  - a. Date of death
  - b. Social Security number (can be found on past joint income tax returns)
  - c. Beneficiary Information: beneficiaries of Will or Trust Name
  - d. Address
  - e. Social Security number
  - f. Relationship to Patient
  
- 3 Heirs' Information. If probate is necessary, the Court requires the following for each heir at law; ask your attorney who heirs at law are.
  - a. Name and address
  - b. Relationship to patient
  - c. Birth date if under age 18
  - d. Last four digits of social security number
  
- 4 Employment benefits. Check with the patient's employer (or former employer if retired) to see if benefits are available. These might be: life insurance, extended health benefits for survivors, and qualified plans (Profit Sharing Plan, Pension Plan, Thrift Plan, 401 (k) plans, TIAA/CREF, V ALIC, Savings Investment Plan, and ESOP).
  
- 5 Social Security Benefits. Visit a Social Security office to inquire about what post-death benefits are available to family members, including the surviving spouse and children under the age of 18 (age 19 if still attending high school).
  
- 6 Safe Deposit Box:
  - a. Location of box
  - b. Location of key
  - c. Name(s) of co-owner(s) [If patient is sole owner, box can only be entered with a Probate Court order after death.]
  - d. Contents of the safe deposit box (Consider reviewing the contents and discarding outdated documents such as life

insurance policies no longer in force or deeds to real estate already sold.)

- 7 Passwords and combinations to computer, to bank accounts, to bill paying, to credit cards, to social security, to safes.
- 8 Bills to be paid on a monthly or quarterly basis, such as mortgage payments and car loans, estimated income tax payments.
- 9 Cost Basis of Gifted Assets:  
When an asset is gifted, it retains the donor's (person who gifts) original cost basis. If the patient has gifted assets, ascertain the cost basis of the donor. The donee (person who receives the gift) will need the cost basis at the future sale of the asset.
- 10 Death Certificates usually required:  
Generally, the family orders five (5) death certificates, keeping in mind the following:
  - a. One is needed for each life insurance company (i.e., if there are multiple policies with one company, only one death certificate needed for that company)
  - b. One is needed for filing Federal Estate Tax Return if necessary. (Check with your attorney about whether a Federal Estate Tax Return will need to be filed.)
  - c. Additional death certificates can be ordered at a later date from the Bureau of Vital Statistics of the county of residence of the patient.
- 11 Funeral Benefits:
  - a. Social Security Death Benefit may be available to a surviving spouse; often funeral home will collect/apply to the funeral bill.
  - b. Veteran's Death Benefit. If the patient is a veteran, call 800-827-1000 to determine if there are benefits available, or check online at [www.va.gov](http://www.va.gov) for information.

G. Resource: An excellent aid in gathering information is a book entitled When I Leave and You Are Left by Mary M. Drakesmith and Jane R. Moerschel who live in St. Charles, Missouri. The cost is \$14.95 and the ISBN# is 0-9655020-7-4. It is a guide to be filled out with information that survivors will need after a death. A portion of the proceeds of the book will be donated to cancer research.

## **XXV. PERSONAL RECORD FILE**

It is helpful to keep all of your records in one place, where family members know where to find it. You may want to put important documents and records in a large envelope or file folder with the contents marked on the outside. Here is a checklist of documents you may want to include. You can also note where to find them on the line to the right of each item.

- A. Will (with your attorney's name and address): \_\_\_\_\_  
\_\_\_\_\_
- B. Insurance policies: \_\_\_\_\_  
\_\_\_\_\_
- C. Records about your home (purchase information, real estate deeds, title, closing statements, mortgages, record of mortgage payments, tax information, details about improvements made, etc.) \_\_\_\_\_  
\_\_\_\_\_
- D. Investment information (broker's name and address, stock certificates and bonds, account reports) \_\_\_\_\_  
\_\_\_\_\_
- E. Bank information (bank name, account numbers, savings bank books, names of officers with whom you have worked) \_\_\_\_\_  
\_\_\_\_\_
- F. Other assets (loans, accounts receivable, land or property ownership, etc.) \_\_\_\_\_  
\_\_\_\_\_
- G. Safe deposit box key (with name of bank and box number) \_\_\_\_\_  
\_\_\_\_\_
- H. Income tax returns (from past three years) and information to prepare current year's return \_\_\_\_\_  
\_\_\_\_\_
- I. Birth certificates (for you and family members) \_\_\_\_\_
- J. Marriage certificates (and/or proof of divorce) \_\_\_\_\_  
\_\_\_\_\_

K. Car/other vehicle title and registration \_\_\_\_\_  
\_\_\_\_\_

L. Social Security card (or record of Social Security number) \_\_\_\_\_  
\_\_\_\_\_

M. Veteran's discharge papers and/or military records \_\_\_\_\_

N. Burial instructions (location, plot, funeral home) \_\_\_\_\_  
\_\_\_\_\_

O. Other instructions to surviving family members \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_



## **XXVII. CAREGIVER RESOURCES**

### **Take Care of Yourself**

As a caregiver, you also need care. Being a caregiver is physically and emotionally draining, but in this labor of love you have the opportunity to strengthen and grow your relationship with the one receiving care. You are building memories and giving a gift that cannot be matched by any other and you become an expert on the person who needs care. Work with the Hospice Team, ask questions, let us know what you need, and most importantly of all, take care of yourself so that you will be able to care for your loved one. Your emotional and physical well-being are important and both may be difficult to maintain.

### **Strategies for Staying Healthy**

- Accept help - let friends, family, hospice volunteers and others support you in doing tasks such as running errands, yard work or sitting with the patient while you take a walk or a nap.
- Take time for you - even a few quiet moments to yourself can be refreshing. You need to take part in activities you enjoy as part of the caregiving routine. Try to set a goal of one outing per week
- Pay attention to your physical needs - eating, sleeping and exercising are important. Do not become so busy being a caregiver that you forget about your own needs.
- Practice relaxation – pause now and then for five minutes and breathe deeply. Focus on pleasant images while sitting in a relaxed state.
- Laughter and keeping your sense of humor are important, too; seek out amusement

### **SUPPORT AGENCIES & SITES:**

Administration on Aging     [www.aoa.gov](http://www.aoa.gov)

National Center on Caregiving     [www.caregiver.org](http://www.caregiver.org)

National Hospice & Palliative Care Organization     [www.nhpco.org](http://www.nhpco.org)

Johnson & Johnson—The Caregiver Initiative     [www.strengthforcaring.com](http://www.strengthforcaring.com)

Caregiving Today Magazine     [www.cargivingtodaymagazine.com](http://www.cargivingtodaymagazine.com)

National Alliance for Caregiving     [www.caregiving.org](http://www.caregiving.org)

## **XXVIII. BJC Home Care & Hospice Locations**

<p><b>BJC Home Care-Alton</b> 3535 College Avenue, Suite B Alton IL 62002 618.463.7541 618.463.7466 fax</p> <p><b>BJC Hospice-Alton</b> One Professional Drive, Suite 180 Alton IL 62002 618.463.7100 618.463.7127 fax</p> <p><b>BJC Home Infusion Therapy</b> 1935 Beltway Drive St. Louis MO 63114 314.953.2000 314.953.2130 fax</p> <p><b>BJC Home Medical Equipment</b> 1935 Beltway Drive St. Louis MO 63114 314.953.2000 314.953.2132 fax</p> <p><b>BJC Home Medical Equipment-Farmington</b> 301 North Washington Street Farmington MO 63640 573.747.1047 573.747.1059 fax</p>	<p><b>BJC Home Care-Metro</b> 4353 Clayton Avenue, Suite 128 St. Louis MO 63110 314.362.0200 314.362.0910 fax</p> <p><b>BJC Home Care, Hospice, InHome-Parkland</b> 757 Weber Road Farmington MO 63640 573.760.8575 573.760.8565 fax</p> <p><b>BJC Home Care &amp; Hospice -Sullivan</b> 153 East Springfield Road Sullivan MO 63080 573.468.5167 573.468.7301 fax</p> <p><b>BJC Home Care &amp; Hospice Administration</b> 9890 Clayton Road St. Louis MO 63124 314.953-1840 314.953.1812 fax</p>
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