

By taking medications regularly, it may be possible to minimize the need to take additional medications. Chronic pain is more easily managed with fewer medications when pain is kept at low levels and is prevented by taking medications regularly.

Pain may contribute to other problems, such as nausea and vomiting, irritability, confusion, loss of sleep, and immobility. Most people have a better quality of life when they are pain free or experiencing low levels of discomfort.

Pain and discomfort can also be managed by other methods. Meditation, music, or guided imagery can allow your mind to relax and reduce the pain. Use of cool or warm packs, or changing position may also assist in soothing aches. Massage may help to decrease discomfort by increasing circulation and relaxing muscles. Your hospice team may be able to assist you with these techniques or direct you to other resources.

Taking Your Medication Safely

- Take only medication **PRESCRIBED** for you;
- If you are unsure of how to take your medication contact your nurse;
- **ALWAYS** take your medication as directed;
- Tell your nurse if you are having difficulty taking your medication, such as swallowing difficulty;
- Space the times you take your medicines as evenly as possible;
Once-a-day: Take once each day at the same time everyday.
Two-times-a-day: Take once in the morning, once in the evening.
Three-times-a-day: Take once in the morning, once in the afternoon, and once in the evening.
Before meals: Take ½ hour before you eat.
- Many pain medications are ordered as needed, or so many hours. It is **IMPORTANT** to **AVOID** allowing pain to become intense before “Taking” the next dose;
- Take your regularly scheduled pain medication even if your pain is controlled;
- If you are having pain you will not become addicted to the medication. You may build a tolerance and the medication frequency or dosage may need adjusting. A different medication may be needed;
- Any medication may produce unwanted side effects. Tell your nurse of new symptoms or concerns you think may be related to your medication;
- Be sure to tell your nurse of any **ALLERGIES**.

Dizziness

Dizziness is a symptom that may occur from several different causes. Following are a few suggestions to assist with this symptom. Safety is the primary concern.

- Rise out of the chair or the bed slowly, allowing your feet to dangle at the side of the bed first. Frequently, dizziness will go away after 1-2 minutes;
- Change positions slowly and use a cane or walker if available;
- Maintain a safe environment. Keep objects out of the area where you will be walking. Ask for assistance if you feel unsteady;
- If you are dizzy, drowsy, or very tired, avoid activities like driving, cooking, or handling machinery;
- If tolerated, increase fluids. Drinking things such as Gatorade® or Pedialyte® can be especially helpful.

Nausea and Vomiting

Sometimes patients experience nausea and vomiting. The following suggestions may help:

- Eat small, frequent meals;
- Avoid liquids at mealtime—drink them an hour after meals;
- Eat dry foods such as toast and crackers;
- Avoid spicy, fried, and fatty food, red meat and food with a strong odor;
- Pay close attention to mouth care;
- Take anti-nausea medication when prescribed (regularly or prior to meals);
- Unless instructed not to, take medications with small amounts of food or milk;
- Serve food cold or at room temperature to decrease its smell and taste;
- The nausea caused by pain medication can feel like motion sickness. If this happens, try resting quietly. If you suspect your pain medicines are making you sick, tell your nurse.

Constipation

When people are very ill, many things can affect how their bowels function. Change in diet, activity, and the use of some medications can produce constipation. This is because the narcotic in the pain medicine slows down the bowel, allowing too much water to be absorbed from the waste matter. The result is a sluggish bowel with hard, dry stool.

Treatment is aimed at speeding up (stimulating) the bowel and/or putting more water into the stool. The medicines often prescribed are supposed to prevent constipation. It is important that you take them routinely as directed by your doctor or nurse. You can also increase fluid intake and activity, as tolerated, to help decrease constipation.

Bowel problems to report to the nurse:

- Very hard, difficult to pass stool;
- More than three days without a bowel movement;
- Constipation followed by diarrhea;
- Constantly passing only smears of stool or liquid stool;
- Blood with the stool;
- Abdominal pain.

Your nurse may advise you to use the following fruit paste recipe:

Anti-constipation Fruit Paste

(Dose: 1-2 tablespoons per day)

¼ pound prunes	¼ cup brown sugar
1 ounce senna tea*	¼ pound figs
¼ pound raisins or pitted dates	¼ cup lemon juice

Prepare the tea using ¾ cup boiling water. Steep for 5 minutes. Strain the tea and pour ½ cup into a large pot. Add fruit and boil for 5 minutes. Remove from heat, add sugar and lemon juice. Allow mixture to cool. Use hand mixer, food processor, or blender, turn fruit mixture into a smooth paste. Spoon into jar or airtight container and place in freezer. Note: the fruit paste does not freeze solid but keeps indefinitely in the freezer.

Serving ideas—on toast, on hot cereal, in ice cream, yogurt, etc.

**Senna tea can be found in health food stores, grocery stores, and pharmacies.*

Dry or Sore Mouth

Good mouth care is very important. Decreased fluid intake, some medications, or physical conditions can leave your mouth dry and/or sore. The following are suggestions to ease some of the discomfort of a dry and sore mouth.

Dry Mouth

Avoid smoking, drinking alcohol, and eating spicy foods. Try Popsicles, shakes, yogurt, pineapple chunks, gum, or hard candy such as lemon drops.

- Drink plenty of fluids;
- Rinse your mouth frequently;
- Take good care of your teeth and gums by flossing and brushing regularly. Using a soft tooth brush may be helpful if your mouth is sore;
- The nurse may also have “toothettes” which are sponges on a stick. They can be used with water to moisten the mouth and for general mouth care. Avoid the use of lemon glycerin swabs because they dry people’s mouths.

Sore Mouth

- Avoid acidic foods like orange juice, tomato juice, and citrus fruit;
- Use a straw to prevent liquids from coming in contact with sores;
- If dentures are too loose, have them adjusted and remove them while sores on the gums are healing;
- Some people get white patches of yeast in their mouths. If this happens, the nurse will seek to obtain medications to ease the discomfort.

Food and Eating

It is common for people to lose their appetite when ill. This may be from the disease itself, treatments, medications, pain, or simply changes in the way food tastes. The body’s need for calories and protein-rich foods is altered because of decreases in activity, exercise, and general metabolism.

Suggestions for eating when appetite is diminished:

- Eat frequent, small meals;
- Drink liquid breakfast drinks, canned supplements such as Ensure, or homemade high-calorie shakes;
- Add dried milk or dried protein powder to liquid or soft foods to add calories;
- Drink fruit juices, such as prune or apricot nectars, to provide additional calories;
- Eat and drink favorite foods;
- Give liquids in other forms, such as Jell-O, pudding, Popsicles and ice cream;
- Avoid using straws, which may increase the swallowing of air, leading to burping or nausea;
- Refer to the instructions on dietary supplements for storage, use, and expiration date.

When our bodies are able to heal, we need proper nutrition to regain strength. However, when our bodies are not able to heal (often the last weeks of life) food can become an unnecessary burden and a source of discomfort. A decreased appetite can create anxiety and tension for both the patient and caregiver. Attempting to force oneself to eat may drain precious energy and lead to nausea and vomiting at a time when the body is saying “no” to food or fluids. Loss of appetite and diminished fluid intake is a part of normal dying. As a caregiver, providing nourishment to the patient may feel like “the only thing left I can do.” Speaking with the hospice nurses, and sharing your feelings with the patient, may help you through this uncomfortable issue.

Skin Problems

Superficial skin sores, pressure sores or bed sores affect some people. They are caused primarily by a decrease in skin health and extended time in bed or a chair. Prevention is the best cure for skin problems.

Here are a few tips on how to avoid bed sores:

- Change positions in bed by turning from side to side every four hours;
- If able, get out of bed and sit in a chair;
- Gently rub the skin with lotion to increase circulation;
- Keep skin clean and dry;
- Change soiled or wet linens and clothing as needed to keep patient dry;
- Clean the skin regularly of any drainage, blood or urine;
- Use pillows to support the leg and back when lying on your side;
- Use a special mattress on the bed, such as an egg crate foam pad, sheepskin, or air mattress;
- Apply protective pads to bony areas like the heels, elbows, and tailbone as recommended by your nurse.

The hospice team may have other suggestions depending on your situation. If you notice any redness, sores or bruises on the patient, communicate this to your nurse.

Emotional Withdrawal

It is common for the terminally ill to begin withdrawal from their familiar activities, such as work, hobbies, relationships, and so on. The need to communicate with others may be lost. Words may lose their importance. Touch and silently being with the patient may become more meaningful. Withdrawal is often used by patients to conserve energy and for self-reflection. Life review may become an important task. The hospice staff is available to assist in this life review process with patients, friends, and families. You should discuss with hospice staff your questions and concerns about signs of your loved one’s emotional withdrawal.

Disorientation/Symbolic Language

One or two weeks prior to death, the patient may begin to sleep most of the time. It becomes difficult for the patient to keep their eyes open. They may become disoriented to time and place. Patients often become confused, talk or gesture to people who are not present or those who have already died. They may speak in what is often referred to as Symbolic Language.

This may include statements like “*I’ve got to pack for my trip,*” or “*I’ve got to cross the bridge now.*” These activities are normal and can be reassuring and calming for the patient.

If you have questions or concerns, speak with the hospice staff.

Information And Skills For Caregivers

Rule No. 1: Don't Forget to Take Good Care of Yourself

Taking Good Care of Yourself

Caregivers also need to receive care. Your emotional and physical well-being are very important and often difficult to maintain. Small things you do for yourself can make a *big difference*. It is important that those in the role of caregiver care for themselves. This will allow the best care to be provided to your loved one.

Some suggestions are:

- **Accept help**

Friends, family, hospice volunteers, and hired assistants can be a great source of support. Accepting this help is a good way to involve those people, as well as a way to take a necessary break yourself. In accepting help, it is best if you can be specific about your needs. Ask someone to run errands, do yard work, bring food, sit with the patient while you go for a walk or take a nap.

- **Take time for yourself**

A few quiet moments can be renewing. A walk with a friend can help you reestablish your perspective. A bath, while someone else cares for the patient, can ease the aches of body and soul. It is important to make time for yourself and identify pleasurable activities as a part of the care giving routine. Try to set a goal of at least one outing per week. This kind of personal time allows you to focus on other aspects of life.

- **Pay attention to your own physical needs**

You may become so busy being a caregiver that you forget about your own needs. Eating, sleeping, and exercising can make a big difference in your outlook. Healthy frozen dinners, meals prepared by a friend, a nap to offset missed sleep, and/or a short walk around the block can really help.

- **Practice relaxation techniques**

Pause for five minutes and breathe deeply. Count breaths or focus on pleasant images while sitting in a relaxed state in a quiet place. Try this especially when someone else is providing the patient's care (like when a hospice team member stops by). Don't forget that laughter and keeping your sense of humor are important, too.

Care for Someone in Bed

As people become weaker, they stay in bed and/or chairs longer. Changing position is important. Often, as people become weaker they do not move easily on their own. Moving and changing positions can ease some of the discomfort that may occur. Changing positions every 2-4 hours prevents pressure sores and stiffness. The changes can be only a small amount and yet relieve the pressure. Ask the nurse about using an egg crate and/or air mattress.

When caring for someone in bed, the following can be helpful to simplify the process:

- Explain what you are doing. The more someone knows what you are doing, the more they can cooperate and let you know how they would like to be turned;
- Provide pain medication prior to movement, if uncomfortable;
- Two people can move someone easier than one;
- Keep any tubing free from being blocked off or pulled on.

Body Mechanics (Back Safety)

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