



# Caring for the Patient With Cancer at Home: A Guide for Patients and Families

Advances in cancer treatment and changing health care systems have led to shorter hospital stays and sicker people being cared for at home. Non-medical caregivers find themselves taking on roles that, just a short time ago, were carried out by trained health professionals. This guide gives you general information about caring for a person with cancer at home. It lists the more common problems people with cancer experience, signs of problems you can look for, and some ideas for things you can do if problems come up. The information given here is not meant to replace talking with your doctor or nurse. The people who know your situation well can give you the information that you will need the most.

We have many other materials on cancer and cancer treatment that may be helpful to you. You can get them from the local office of your American Cancer Society, on our Web site at [www.cancer.org](http://www.cancer.org), or by calling 1-800-227-2345.

Trade names are used in this guide because they are well known. Their use does not represent any previous testing or backing by the American Cancer Society. Generic and other brands may be recommended by your doctor or cancer care team.

## Anxiety and fear

Anxiety (a feeling of worry or unease) and fear are common feelings that patients and families sometimes have when coping with cancer. These feelings are normal responses to the stress of cancer, and may be more noticeable around the time the cancer is first diagnosed. Feelings of fear or anxiety may be due to changes in the ability to continue family duties, loss of control over events in life, changes in appearance or body image, or simply the shock of a cancer diagnosis. They may involve uncertainty about the future and concerns about suffering, pain, and the unknown. Fears around loss of independence, changes in relationships with loved ones, and becoming a burden to others may overwhelm the patient and complicate family life.

Family members may have these feelings because they, too, are uncertain about the future or angry that their loved one has cancer. They may feel guilt and frustration at not being able to "do enough." Or they may feel overwhelmed by everything they now have to do. Many caregivers feel stressed because of problems balancing work, child care, self-care, and other tasks, along with more responsibility at home. All of this is on top of having to worry about and take care of the person with cancer.

Sometimes, a person with cancer may become overly anxious, fearful, or depressed and may no longer cope well with his day-to-day life. If this happens, it often helps the patient and family to get help from a professional therapist or counselor.

## What to look for

- Feeling anxious
- Trouble thinking or solving problems
- Being nervous, agitated, irritable, or restless
- Feeling or looking tense
- Concern about "losing control"
- An uneasy sense that something bad is going to happen
- Trembling and shaking
- Headaches
- Being cranky or angry with others
- Tiredness or fatigue
- Trouble sleeping or restless sleep

## What the patient can do

- Talk about feelings and fears that you or family members may have – it's OK to feel sad and frustrated.
- Decide together with your family or caregiver what things you can do to support each other.
- Do not blame yourself and others when you feel anxious and afraid. Instead, look at your emotions, concerns, and beliefs about what has been going on in your life, and talk about those things.
- Get help through counseling and support groups.
- Use prayer, meditation, or other types of spiritual support.

- Try deep breathing and relaxation exercises several times a day. (For example, close your eyes, breathe deeply, focus on each body part, and relax it, starting with your toes and working up to your head. When you're relaxed, imagine yourself in a pleasant place, such as a breezy beach or a sunny meadow.)
- Cut down on caffeine. It can worsen anxiety symptoms.
- Think about asking your doctor or nurse for a referral to a counselor who can work with you and your family.
- Talk with your doctor about the possible use of medicine for anxiety.

## What caregivers can do

- Gently invite the patient to talk about his fears and concerns.
- Do not try to force the patient to talk before he is ready.
- Listen carefully without judging the patient's feelings, or your own.
- Decide together with the patient what you can do to support each other.
- For severe anxiety, it is usually not helpful to try to reason with the patient. Instead, talk with a doctor about the symptoms and problems you notice.
- To reduce your own stress, try suggestions from the list for the patient or use any others that have worked for you in the past.
- Consider getting support for yourself through groups or individual counseling.

## Call the doctor if the patient:

- Has trouble breathing
- Is sweating, with a fast or pounding heartbeat
- Is feeling very restless

Note that some medicines or supplements can cause or worsen anxiety symptoms. If anxiety gets worse after a new medicine is started, talk with your doctor about it.

For more in-depth information on anxiety and fear, call us at 1-800-227-2345 and ask for a copy of *Anxiety, Fear, and Depression*, or read it on our Web site.

## Appetite, poor

A person with a poor appetite or no appetite may eat much less than he normally does or may not eat at all. A poor appetite can be caused by many things, such as trouble swallowing, depression, pain, nausea, or vomiting. (For more information on these causes, see the related sections.) A poor appetite can also be due to a changed sense of

taste or smell, feeling full, tumor growth, dehydration (see the section called "Fluids and dehydration"), or side effects of chemotherapy or radiation. A poor appetite is most often a short-term problem.

## What to look for

- Lack of interest in food
- Refusing to eat favorite foods
- Weight loss

## What the patient can do

- Talk with your doctor about what may be causing your poor appetite.
- Eat as much as you want to, but don't force yourself to eat.
- Think of food as a necessary part of treatment.
- Start the day with breakfast.
- Eat small, frequent meals of favorite foods.
- Try foods high in calories that are easy to eat (such as pudding, gelatin, ice cream, sherbet, yogurt, or milkshakes).
- Add sauces and gravies to meats, and cut meats into small pieces to make them easy to swallow.
- Use butter, oils, syrups, and milk in foods to increase calories. Avoid low-fat foods unless fats cause heartburn or other problems.
- Try strong flavorings or spices.
- Create pleasant settings for meals. Soft music, conversation, and other distractions may help you eat better.
- Eat with other family members.
- Drink liquids between meals instead of with meals. (Liquids at mealtime can lead to early fullness.)
- Try light exercise an hour before meals.
- Hard candies, mint tea, or ginger ale may help get rid of strange tastes in the mouth.
- With your doctor's OK, enjoy a glass of beer or wine before eating.
- Eat a snack at bedtime.

- When you don't feel like eating, try liquid meals, such as flavored supplements (such as Ensure<sup>®</sup>, Sustacal<sup>®</sup>, Boost<sup>®</sup>, Carnation Instant Breakfast<sup>®</sup>, and others). Using a straw may help.

## What caregivers can do

- Try giving the patient 6 to 8 small meals and snacks each day.
- Offer starchy foods (such as bread, pasta, or potatoes) with high-protein foods, such as fish, chicken, meats, turkey, eggs, cheeses, milk, tofu, nuts, peanut butter, yogurt, peas, and beans.
- Keep cool drinks and juices within the patient's reach.
- If the smell of food bothers the patient, offer bland foods served cold or at room temperature.
- Create pleasant settings for meals, and eat with the patient.
- Offer fruit smoothies, milkshakes, or liquid meals when the patient doesn't want to eat.
- Try plastic forks and knives instead of metal if the patient is bothered by bitter or metallic tastes.
- Don't blame yourself when the patient refuses food or can't eat.
- If the patient cannot eat, you may want to offer just your company. Or offer to read to them or give them a massage.

## Call the doctor if the patient:

- Feels nauseated and cannot eat for a day or more
- Loses 5 pounds or more
- Feels pain when he eats
- Does not urinate for an entire day or does not move bowels for 2 days or more
- Does not urinate often, and when he does, the urine comes out in small amounts, smells strong, or is dark colored
- Vomits for more than 24 hours
- Is unable to drink or keep down liquids
- Has pain that is not controlled

# Blood counts

Blood counts measure 3 important parts of blood:

The *hemoglobin* percentage measures the ability of the red blood cells to carry oxygen. A normal hemoglobin range is about 14.5 to 18 for men and 12 to 16 for women. Most people still feel well with a hemoglobin percentage as low as 10. A low hemoglobin level is called anemia.

The *white blood cell* count measures your body's ability to fight infection. A normal white blood cell count is about 5,000 to 10,000. A low white blood cell count may put you at higher risk of infection. You will want to watch for signs of infection so that you can go to your doctor for treatment right away. A high white blood cell count may be a sign of an infection, or it may be due to certain types of disease.

The *platelet* count looks at the cells that help your blood to clot. A normal platelet count is about 150,000 to 450,000. Normal clotting is still possible with a platelet count of 100,000. Dangerous bleeding may occur when the platelet count goes below 20,000.

After cancer treatment, it may take a few weeks for your counts to get back to normal. If you see any other doctors or dentists during this time, be sure they know your counts are low. Some very common treatments may cause problems for you. Call the American Cancer Society at 1-800-227-2345 and ask for a copy of *Understanding Your Lab Test Results*, or read it on our Web site if you would like to know more about what your lab values mean.

## *Low hemoglobin*

### What to look for

- New or worsening tiredness that makes it harder to do your regular activities
- Chest pain or shortness of breath
- Pale skin, nail beds, or gums
- Dizziness
- Weakness
- Blood in stool (bright red, dark red, or black stools)
- Vomiting dark brown or bright red material

(The last 2 are signs of bleeding, which can cause anemia.)

### What the patient can do

- Balance rest and activities.

- Tell the doctor if you're not able to get around as well as usual.
- Plan your important activities when you have the most energy.
- Eat a balanced diet that includes protein (meat, eggs, cheese, and legumes such as peas and beans), and drink 8-10 glasses of water a day, unless your care team gives you other instructions.

## What caregivers can do

- Help schedule friends and family members to prepare meals, clean house, do yard work, or run errands for the patient.
- Watch for confusion, faintness, or dizziness, as noted below.

## **Call the doctor if the patient:**

- Has chest pains
- Has shortness of breath when resting
- Feels dizzy or faint
- Becomes confused or cannot concentrate
- Has not been able to get out of bed for more than 24 hours
- Has blood in his stool
- Vomits dark brown or bright red material

## *Low white blood cell count*

## What to look for

- Temperature of more than 100.5° F when taken by mouth
- Any new area of redness or swelling
- Pus or yellowish discharge from an injury or other location
- New cough or shortness of breath
- New abdominal pain
- Shaking chills that may be followed by sweating
- Burning or pain when urinating
- Sore throat

- Sores or white patches in the mouth

## What the patient can do

- Check your temperature by mouth or under your armpit if you can't keep a thermometer in your mouth.
- Take acetaminophen (Tylenol<sup>®</sup>) for a fever after calling your doctor.
- Keep warm.
- Take antibiotics or other medicine as prescribed.
- Drink fluids, but do not force more than you can tolerate.
- Avoid anything that can cause cuts in the skin.
- Wash cuts and scrapes with soap and water every day, apply antibiotic ointment, and keep them covered until healed.
- Keep your body clean by bathing daily and washing your hands after using the bathroom.
- Avoid crowds, and don't visit with people who have infections, coughs, or fevers.
- Talk with your doctor or nurse about eating raw fruits and vegetables. Some suggest eating only cooked fruits and vegetables until the white blood cell counts come up again. If you eat raw foods, wash them carefully and peel them to avoid germs.
- Keep your mouth clean by brushing your teeth twice a day and flossing once a day (unless you were told not to floss).
- Drink 2 to 3 quarts of liquid each day, if your doctor approves.

## What caregivers can do

- Watch for shaking chills, and check the patient's temperature after the shaking stops.
- Check the patient's temperature by placing the thermometer in the patient's mouth or under his armpit. (Do not take a rectal temperature.)
- Encourage visitors who have fevers or the flu to visit the patient only by phone until they are well.
- Offer extra fluids.
- Help the patient take medicines on schedule.

## **Call the doctor if the patient:**

- Has a temperature of more than 100.5° F when taken by mouth
- Has shaking chills
- Feels or seems "different" to others
- Cannot take fluids

## *Low platelet count*

### What to look for

- Bleeding from anywhere (such as mouth, nose, or rectum)
- New bruises on the skin
- Red rash that looks like pinpoint dots, usually starting on feet and legs
- Bad headaches, dizziness, or blurred vision
- Weakness that gets worse
- Pain in joints or muscles
- Vomiting blood or dark material that looks like coffee grounds
- Blood in stool (bright red, dark red, or black stools)
- More than the usual amount of vaginal bleeding during monthly periods

### What the patient can do

- Use only an electric razor (not blade) for shaving.
- Avoid contact sports (such as wrestling, boxing, or football) and any other activities that might result in injury.
- Protect your skin from cuts, scrapes, and sharp objects.
- Use a soft toothbrush.
- If your mouth is bleeding, rinse it out with cold water.
- Talk to your doctor or nurse about whether you should put off flossing your teeth until platelet counts improve.
- Do not blow your nose or cough with great force.

- Stay upright; keep your head level with or above your heart.
- Use a stool softener to avoid constipation and straining during a bowel movement. Do not use enemas or suppositories of any kind. (See the section called "Constipation.")
  - 1) If constipated, see the section called "Constipation." Check with your doctor before using laxatives.
- Do not put anything in the rectum, including suppositories, enemas, thermometers, etc.
- Stay away from anti-inflammatory pain medicines, such as naproxen or ibuprofen, or medicines that contain aspirin unless your doctor tells you to use them.
- If bleeding starts, stay calm. Sit or lie down and get help.

## What caregivers can do

- For nosebleeds, have the patient sit up with head tilted forward, to keep blood from dripping down the back of the throat. Put ice on the nose and pinch the nostrils shut for 5 minutes before releasing them. Ice on the back of the neck may also help.
- For bleeding from other areas, press on the bleeding area with a clean, dry washcloth until bleeding stops.

## Call the doctor if the patient:

- Has bleeding or any of the symptoms listed in the "What to look for" section
- Has trouble speaking or moving

## Blood in stool

Blood in the stool may be caused by irritation of the bowel during a bowel movement. It can also be caused by straining very hard, by an ulcer or a tumor in the bowel, by hemorrhoids (enlarged blood vessels in or around the anus), by a pressure sore or ulcer in the anal area, or by a low platelet count. (See the section called "Blood counts.")

## What to look for

- Blood on toilet tissue
- Blood on underwear, sheets, or underpads
- Streaks of blood in stool
- Bright red blood from rectum

- Dark red or black bowel movements (But remember that eating beets can cause red stools, and iron tablets or bismuth medicines such as Pepto-Bismol<sup>®</sup> and Kaopectate<sup>®</sup> can cause black stools for a short time. This is normal.)

## What the patient can do

- Check how much blood is being passed.
- Avoid placing anything in the rectum, including suppositories, enemas, thermometers, etc.
- Keep stool soft by taking in plenty of fluids and fiber.
- Use stool softeners.
- Wash anal area very carefully with warm, soapy water, rinse well, and pat dry.
- Take a sitz bath (sitting in warm water), which may be helpful for hemorrhoids.

## What caregivers can do

- Help the patient watch for bleeding.
- Offer extra fluids, fruits, and vegetables to keep the patient's stool soft.

### **Call the doctor if the patient:**

- Has blood on toilet tissue 2 or more times
- Has blood streaks in stool
- Has bright red blood from rectum
- Has dark red or black stools

## **Blood in urine**

Blood can be seen in the urine when a patient is bleeding in some part of his urinary system and the blood is being flushed out along with the urine. Common causes include urinary tract infections (UTIs), an injury to the urinary tract, kidney or bladder stones, a tumor growing in the urinary tract, or a low platelet count. (See the section called "Blood counts.")

## What to look for

- Red, pink, or tea-colored urine

- Blood or clots in urine
- Pain with urination

## What the patient can do

- Drink about 1 quart of water (or other fluids) during each 8-hour period (3 quarts each day), unless your doctor has limited the amount you can drink.
- Take medicines as prescribed.

## What caregivers can do

- Offer extra fluids.
- Help the patient watch his urine, if needed.

## Call the doctor if the patient:

- Sees blood in the urine or discolored urine
- Has pain in lower back or on lower sides of back when urinating
- Has pink, cloudy, or foul-smelling urine
- Has symptoms that do not improve after treatment
- Has a sudden, urgent need to urinate
- Urinates more often than usual
- Is unable to urinate
- Has a fever of more than 100.5° F when taken by mouth, or shaking chills
- Is confused or feels or seems "different" to others

## Confusion

When the thought process is disturbed, or when a person has trouble thinking and acting like he normally does, he may be confused. There can be many causes of confusion, including:

- Low blood sugar
- Infection
- High fever

- Tumor spread into the brain
- Cancer in the fluid surrounding the brain
- Lack of oxygen to the brain
- Too much calcium in the blood
- Intense pain
- Too much pain medicine

Confusion can start or get worse when the patient goes to a new place and may worsen at night. Usually the cause of the confusion can and should be treated.

If a person becomes confused, call the doctor right away. The patient may need to see the doctor quickly so the cause of the problem can be found and treated. Sometimes, the patient may need to be in the hospital until the problem is treated. During this time, it is helpful for confused patients to have someone they know stay with them.

## What to look for

- Sudden change in ability to speak, especially long pauses or slurred words
- Trouble staying alert or paying attention
- Patient needs help bathing and dressing when he was able to manage alone before
- Cloudy, disorganized thinking or the patient not knowing where he is
- Sudden changes in emotion; for instance, quick shifts from happy to irritated
- Forgetting what he is doing

## What the patient can do

- Call the doctor right away if you realize you are having periods of confusion.
- Ask someone to stay with you to help keep you safe.

## What caregivers can do

- Go to doctor's appointments with the patient so that you can describe the patient's problems and remember instructions for him.
- Focus attention by gently touching the patient and facing the patient when talking to him.
- Stay within a few feet of the patient when you are talking to him.

- Always tell the patient who you are.
- Turn off the radio or TV when you are talking.
- Talk slowly and use short sentences.
- Tell the patient the date, time, and where he is.
- Keep a calendar and clock where the patient can see them.
- Tell the patient just before you start doing something (such as changing the bed, dressing, or bathing them), and explain each step as you go along.
- Play soft, soothing music when the patient is in the room alone.
- Use a night-light so that the patient can see where he is.
- Label commonly used items with pictures. For example, put a picture of a toilet on the bathroom door and a picture of a flame over the stove.
- Protect the patient from injury.
- Help the patient with washing, going to the bathroom, and other daily activities that may be hard for him to do alone.
- Check to see what the patient eats. (He may forget to eat, or may not be able to eat.)
- Be sure that the patient takes the right medicines as prescribed.
- Keep medicines out of reach between doses.

### **Call the doctor if the patient:**

- Becomes confused suddenly or if confusion worsens
- Has any sudden changes in his ability to do routine tasks or care for himself
- Becomes violent
- Hurts himself in some way

## **Constipation**

Constipation is the infrequent or difficult passage of hard stool (feces), which often causes pain and discomfort. It is caused by too little fluid or not enough movement in the bowel. Lack of activity, weakness, ignoring the urge to have a bowel movement, pain medicine, or poor food and fluid intake can all add to this problem.

## What to look for

- Small, hard bowel movements
- Leakage of soft, liquid stool that looks like diarrhea
- Stomach ache or cramps
- Passing a lot of gas or frequent belching
- Belly looks blown up or puffy
- No regular bowel movement within the past 3 days
- Vomiting or nausea
- Feeling of fullness or discomfort

## What the patient can do

- Drink more fluids. Pasteurized fruit juices and warm or hot fluids in the morning are especially helpful.
- Increase the amount of fiber in the daily diet by eating foods such as: whole-grain breads and cereals; fresh raw fruits with skins and seeds; fresh, raw vegetables; fruit juices; and dates, apricots, raisins, prunes, prune juice, and nuts.
- Avoid foods and drinks that cause gas, such as cabbage, broccoli, and fizzy drinks.
- Avoid or cut back on any foods that make you constipated, such as cheese or eggs.
- Get as much light exercise as you can.
- Do not use enemas or suppositories. Use stool softeners or laxatives only after talking with your doctor or nurse.
- Go to the bathroom as soon as you have the urge to have a bowel movement.
- Keep a record of bowel movements so that problems can be noticed quickly.

## What caregivers can do

- Offer prune juice, hot lemon water, coffee, or tea to help stimulate bowel movements.
- Encourage extra fluids.
- Help keep a record of bowel movements.
- Offer high-fiber foods, such as whole grains, dried fruits, and bran.
- Talk with the doctor before using laxatives.

## **Call the doctor if the patient:**

- Has not had a bowel movement in 3 days
- Has blood in or around the anal area or in the stool (See the section called "Blood in stool.")
- Cannot move bowels within 1 or 2 days after taking laxative
- Has cramps or vomiting that doesn't stop

## **Depression**

Some degree of depression is common when patients and family members are coping with cancer. Sadness and grief are normal, as are a range of other emotions. But when these feelings last a long time or get in the way of day-to-day activities, there is reason for concern. Clinical depression, a treatable illness, occurs in about 1 in 4 people with cancer. Depression causes greater distress, impaired functioning, and less ability to follow treatment plans. People who have had 1 or more bouts of serious depression are more likely to have depression after their cancer diagnosis.

The symptoms of clinical depression are listed below. Family and friends can look for these symptoms in a cancer patient and encourage him to get help for depression when symptoms are noticed. Patients do not usually have symptoms of anxiety and depression at the same time. (See the section called "Anxiety and fear.")

Treatments for depression in cancer patients include medicine, counseling, or a combination of both, and sometimes other specialized treatments. These treatments improve the depression, reduce the suffering, and help the person with cancer have a better quality of life.

## **What to look for**

### **Symptoms of clinical depression:**

- Sad or "empty" mood almost every day for most of the day
- Loss of interest or pleasure in activities that were once enjoyed
- Eating problems (loss of appetite or overeating), including weight loss or gain\*
- Sleep changes (inability to sleep, early waking, or oversleeping)\*
- Fatigue or decreased energy almost every day\*
- Other people notice that you are restless or "slowed down" almost every day
- Feelings of guilt, worthlessness, and helplessness

- Trouble concentrating, remembering, or making decisions
- Thoughts of death or suicide, or attempts at suicide
- Wide mood swings from depression to periods of agitation and high energy

If 5 or more of the above symptoms last for 2 weeks or longer or are severe enough to hinder normal functioning, an evaluation for clinical depression by a qualified health professional or mental health specialist is recommended.

*\*Physical problems such as fatigue, poor appetite, and sleep changes can also be side effects of cancer treatment, and may linger after cancer treatment is over. Talk to your doctor about the possible causes of these symptoms and whether depression might be a factor.*

## What the patient can do

- Talk about feelings and fears that you or family members may have. It's OK to feel sad and frustrated.
  - 2) Listen carefully to each other.
  - 3) Decide together what you can do to support each other.
  - 4) Encourage, but do not force, one another to talk.
- Seek help through counseling and support groups.
- Use prayer or other types of spiritual support.
- Try deep breathing and relaxation exercises several times a day. (For example, close your eyes, breathe deeply, focus on each body part, and relax it, starting with your toes and working up to your head. When you're relaxed, imagine yourself in a pleasant place, such as a breezy beach or a sunny meadow.)
- Talk with your doctor about possible treatments for anxiety or depression.
- Consider working with a professional counselor to deal with the changes in your life.
- Be sure the doctor has a list of all drugs you are taking before antidepressants are started.
- Take all medicines as prescribed.
- Expect antidepressants to take at least 2 to 4 weeks to improve your depression symptoms. Sometimes, stimulant drugs are used during this time to relieve symptoms.
- Let your doctor know if you are having side effects after starting an antidepressant.
- Avoid alcohol while on an antidepressant unless you check with your doctor or pharmacist.
- Find out if the antidepressant causes drowsiness before you try to drive.

- Do not suddenly stop taking the antidepressant medicine.

## What caregivers can do

- Gently invite the patient to talk about his fears and concerns.
- Do not force the patient to talk before he is ready.
- Listen carefully without judging the patient's feelings or your own. It is OK to point out and disagree with negative or self-defeating thoughts.
- Decide together what you can do to support each other.
- Avoid telling the person to "cheer up" if he is depressed.
- Do not try to reason with the person if fear, anxiety, or depression is severe. Talk with the doctor about medicines and other kinds of help.
- If necessary, help make the appointment for evaluation or treatment and take the patient to the doctor.
- Engage the person in activities he enjoys.
- If the patient starts antidepressants, encourage him to continue treatment until symptoms improve (which may take 2 to 4 weeks) or to seek different treatment if symptoms don't improve.
- Reassure the depressed person that with time and treatment, he will begin to feel better.
- Keep in mind that caregivers can also become depressed. All these suggestions may be used for caregivers, too.
- Take time to care for yourself. Spend time with friends or doing activities you enjoy.
- Consider getting support for yourself through groups or individual counseling.

## Call the doctor if the patient:

- Has thoughts of suicide, or cannot stop thinking about death
- Behaves in such a way that you are concerned for his safety
- Cannot eat or sleep and is not interested in the activities of daily living for several days
- Has trouble breathing, is sweating, or feels restless

For more in-depth information on depression, call your American Cancer Society at 1-800-227-2345 and ask for a copy of *Anxiety, Fear, and Depression*, or read it on our Web site.

# Diarrhea

Diarrhea is the passage of loose or watery stools 3 or more times a day with or without discomfort. It happens when the water in the intestine is not being absorbed back into the body for some reason. Sometimes, diarrhea can be caused by an overflow of intestinal liquids around stool that is lodged in the intestine (impaction). Other causes can include chemotherapy; radiation therapy to the abdomen; medicines; infections; surgery; anxiety; supplemental feedings that contain large amounts of vitamins, minerals, sugar, and electrolytes; and tumor growth. Diarrhea caused by chemotherapy or radiation therapy may last for up to 3 weeks after treatment ends.

## What the patient can do

- Try a clear liquid diet (one that includes water, weak tea, apple juice, peach nectar, clear broth, Popsicles, and gelatin with no solids added) as soon as diarrhea starts or when you feel that it's going to start. Avoid acidic drinks, such as tomato juice, citrus juices, and fizzy soft drinks.
- Eat frequent small meals. Do not eat foods that are very hot or spicy.
- Avoid greasy foods, bran, raw fruits and vegetables, and caffeine.
- Avoid pastries, candies, rich desserts, jellies, preserves, and nuts.
- Do not drink alcohol or use tobacco.
- Avoid milk or milk products if they seem to make diarrhea worse.
- Be sure your diet includes foods that are high in potassium (such as bananas, potatoes, apricots, and sports drinks like Gatorade<sup>®</sup> or Powerade<sup>®</sup>). Potassium is an important mineral that you may lose if you have diarrhea.
- Monitor the amount and frequency of bowel movements.
- Clean your anal area with a mild soap after each bowel movement, rinse well with warm water, and pat dry. Or use baby wipes to clean yourself after each bowel movement.
- Apply a water-repellent ointment, such as A&D Ointment<sup>®</sup> or petroleum jelly, to the anal area.
- Sitting in a tub of warm water or a sitz bath may help reduce discomfort.
- Take medicine for diarrhea as prescribed by your doctor.
- When the diarrhea starts to improve, try eating small amounts of foods that are easy to digest such as rice, bananas, applesauce, yogurt, mashed potatoes, low-fat cottage cheese, and dry toast. If the diarrhea keeps getting better after a day or 2, start small regular meals.

## What caregivers can do

- See that the patient drinks about 3 quarts of fluids each day.
- Keep a record of bowel movements to help decide when the doctor should be called.
- Check with the doctor before using any over-the-counter diarrhea medicine. Many of these contain compounds that are like aspirin, which can worsen bleeding problems. Talk to the doctor about using a prescription medicine.
- Check the anal area for red, scaly, broken skin. If present, see the section called "Skin (pressure) sores."
- Protect the bed and chairs from being soiled by putting pads with plastic backing under the buttocks where the patient will lie down or sit.

### **Call the doctor if the patient:**

- Has 6 or more loose bowel movements a day with no improvement in 2 days
- Has blood in or around anal area or in stool (See the section called "Blood in stool.")
- Loses 5 pounds or more after the diarrhea starts
- Has new abdominal pain or cramps for 2 days or more
- Does not urinate for 12 hours or more
- Does not drink liquids for 48 hours or more
- Has a fever of 100.5° F or higher when taken by mouth
- Gets a puffy or swollen belly
- Has been constipated for several days and then begins to have small amounts of diarrhea or oozing of liquid stool, which could suggest an impaction (severe constipation)

## Exercise

It is important to exercise as much as you can to keep muscles working as well as possible. Exercise helps prevent problems that are caused by long-term bed rest, such as stiff joints, weak muscles, breathing problems, constipation, skin sores, poor appetite, and mental changes. It also helps reduce stress and relieve fatigue. Talk with your doctor about exercises that you can safely do, and then set goals for slowly increasing your physical activity level. If you have trouble moving around, please see the section called "Weakness."

## What the patient can do

- Do as much daily self-care as possible.
- Take a walk every day.
- Do range-of-motion exercises as instructed by your nurse, doctor, or physical therapist. Active range of motion is when you move a joint without any help from others. Passive range of motion is when someone else moves it for you. You can do either type of range-of-motion exercises without getting out of bed. Avoid moving any joint that is painful.

## What caregivers can do

- Go with the patient on walks or other exercise outings.
- Encourage the patient to do as much as possible for himself.
- Talk with the doctor or nurse about range-of-motion exercises if the patient has trouble getting out of bed. You may remind the patient to do active range-of-motion exercises several times a day, if he is able. If not, you may learn to help the patient with passive range of motion.

## Call the doctor if the patient:

- Gets weaker, starts losing his balance, or starts falling
- Has new pain or pain that gets worse
- Has headaches or gets dizzy
- Has blurred vision, new numbness, or tingling in arms or legs

## Falls

A person who is unsteady on his feet, a little confused, or just weak is at high risk for falling. A person who has these problems is likely to fall while trying to get out of bed. Or the patient can fall off the toilet or commode, slip in the bathtub or shower, or tire out and fall as he is walking.

## What the patient can do

- If you notice problems with weakness or poor balance, ask for help getting up or walking.
- If you fall, let your doctor and your caregivers know. They will want to help prevent future falls, and may need to check you for injuries.

- If you have trouble walking, ask your doctor about a home health nursing visit. Home care nurses may be able to make your home safer for you. They also have ways to help you walk more safely.

## What caregivers can do

- When the patient needs to get out of bed, first sit him on the side of the bed for a minute or so. This will help if the change in position causes the patient to be dizzy or unsteady.
- If the patient is unsteady, help him when walking.
- If the patient feels light-headed, stay with the patient when he goes to the bathroom.
- Remind the patient to call for help before trying to get up.
- To help in the tub or shower, use bath mats or non-slip stickers. You can also use a shower stool or chair so the patient can sit while bathing.
- Keep electric cords off the floor. Walking paths need to be clear of clothing, throw rugs, and other items that may cause tripping or slipping.
- Tape the edges of rugs to the floor.
- Have a bedpan or urinal within easy reach.
- If possible, place a commode near the bed, or place the bed near a bathroom.
- The patient should wear shoes or non-skid slippers when walking or standing. Avoid using slippery shoes or open-heel bedroom slippers.
- Ask the doctor about a home health care visit to check your home for ways to prevent falls. Handrails, bedside commodes, grab bars, shower chairs, and other tools can help keep some patients from falling.

## If the patient falls:

- Leave the patient where he has fallen until you can find out if there are serious injuries.
- If the patient is unconscious, bleeding, or has fluid draining from the mouth, ears, or nose, call the doctor or emergency services (911) right away.
- If the patient is not breathing, call 911 unless the patient is in hospice or has a Durable Power of Attorney for Health Care that states his wish not to be revived.
- If the patient can respond to you, ask if he feels any pain.
- Check the patient's head, arms, legs, and buttocks for cuts and bruises, and look to see if the area looks strange or out of shape (possibly due to a broken bone).

- Apply ice packs and pressure to any bleeding area. (Put ice in a plastic bag and wrap bag in a towel.)
- If you cannot move the patient, make him as comfortable as possible until help comes.
- If the patient is not in pain and is not bleeding, help him back to a bed or chair. (If possible, have 2 people move the patient.)

### **Call the doctor if the patient:**

- Notices new weakness, numbness, or change in mental status (such as if the patient is confused, doesn't know where he is, becomes forgetful, or isn't making sense)
- Gets weak or unsteady enough that a fall is likely
- Is not breathing
- Has bleeding, has fluid draining from the mouth, ears, or nose, or is unconscious
- Is concerned about possible injury from a fall

## **Fatigue**

Fatigue is when a person has less energy to do the things he normally does or wants to do. It is the most common side effect of cancer treatment. Cancer treatment fatigue is different from that of everyday life. Fatigue related to cancer treatment can appear suddenly and can be overwhelming. It is not relieved by rest. It can last for months after treatment ends. This type of fatigue can affect many aspects of a person's life, including the ability to do his usual activities.

Cancer fatigue is real and should not be ignored. It can be worse when a person is dehydrated, anemic, in pain, not sleeping well, or has an infection. (See the sections on fluids and dehydration, blood counts, pain, sleep problems, and fever.) Recent studies have shown that exercise programs during treatment can help reduce fatigue.

### **What to look for**

- Feeling like you have no energy
- Sleeping more than normal
- Not wanting to or not being able to do normal activities
- Paying less attention to personal appearance
- Feeling tired even after sleeping
- Trouble thinking or concentrating

- Trouble finding words and speaking

## What the patient can do

- Balance rest and activities.
- Tell the doctor if you're not able to get around as well as usual.
- Plan your important activities for when you have the most energy.
- Schedule important activities throughout the day rather than all at once.
- Get enough rest and sleep. Short naps and rest breaks may be needed.
- Remember that fatigue caused by treatment is short term and that your energy will slowly get better after treatment has ended.
- Ask others to help you by cooking meals and doing housework, yard work, and errands.
- Eat a balanced diet that includes protein (meat, eggs, cheese, and legumes such as peas and beans), and drink about 8 to 10 glasses of water a day, unless your care team gives you other instructions.
- See the section called "Exercise."

## What caregivers can do

- Help schedule friends and family members to prepare meals, clean house, do yard work, or run errands for the patient.
- Try not to push the patient to do more than he is able.
- Help the patient set up a routine for activities during the day.

## **Call the doctor if the patient:**

- Is too tired to get out of bed for more than a 24-hour period
- Becomes confused (see the section called "Confusion") or cannot think clearly
- Has trouble sleeping at night
- Has fatigue that keeps getting worse
- Feels out of breath or has a racing heart after only a small activity

# Fever

Fever is a body temperature of more than 100.5° F (when taken by mouth) that lasts for a day or more. Fever is usually caused by an infection. Infections can be viral (in which case the symptoms can be treated even though there may be no treatment for the cause), or they can be bacterial or fungal (in which case medicines may be prescribed after the infection is diagnosed). Other causes of fever include inflammatory illness, drug reactions, or tumor growth. Sometimes, the cause may not be known. In an infection, the fever is a result of the body "heating up" to try to kill any invading germs. A fever is an important natural defense against germs.

People getting chemo are more likely to have infections because they have lower numbers of the white blood cells needed to fight them. (See the section called "Blood counts.") It is good to have an easy-to-read, easy-to-use, oral thermometer (one made to take your temperature by mouth) so you can check your temperature to see if you have a fever.

## What to look for

- Increased skin temperature
- Feeling warm
- Feeling tired
- Headache
- Feeling cold
- Shaking chills
- Body aches
- Skin rashes
- Any new area of redness or swelling
- Pus or yellowish discharge from an injury or other location
- New cough or shortness of breath
- New abdominal pain
- Burning or pain when urinating
- Sore throat
- The patient is confused, doesn't know where he is, becomes forgetful, or isn't making sense. (See the section called "Confusion.")

## What the patient can do

- If you start feeling warm or cold, check your temperature by mouth every 2 to 3 hours. If you are unable to hold the thermometer in your mouth, put it under your armpit.
- Keep a record of temperature readings.
- Drink a lot of liquids (such as water, fruit juices, cola, Popsicles, and soups).
- Get enough rest.
- Cover yourself with a blanket if you get chilly.
- Cover yourself only with a sheet if you feel hot.
- Use a cold compress on your forehead if you feel hot.
- Take acetaminophen (Tylenol) or other medicines for fever only if your doctor tells you to do so.

## What caregivers can do

- Watch for shaking chills, and check the patient's temperature after the shaking stops.
- Check the patient's temperature by placing the thermometer in mouth or under his armpit. (Do not take the temperature rectally unless the doctor tells you it's OK.)
- Encourage visitors who have fevers or the flu to visit the patient by phone until they are well again.
- Offer extra fluids and snacks.
- Help the patient take medicines on schedule.
- Call the doctor if the patient is confused, doesn't know where he is, becomes forgetful, or isn't making sense. (See the section called "Confusion.")

## **Call the doctor if the patient:**

- Has a temperature of 100.5° F or higher when taken by mouth
- Has 2 or more of the symptoms listed under the "What to look for" section
- Has a fever lasting for more than 24 hours
- Has shaking chills
- Cannot take fluids

# Fluids and dehydration

Everything in the body contains fluid (water). The human body must have a certain amount of liquid, and reduced amounts of fluid in the body can cause changes in how a person feels. Fluid balance means that the body's fluids are properly regulated and in the right places. Swelling is too much water in the body. (If you have this symptom, see the section called "Swelling.") Dehydration is not having enough water in the body or not having enough fluid where it is needed in the body.

## What to look for

- Dry mouth, thirst
- Dizziness, weakness, constipation (See the section called "Constipation.")
- Trouble swallowing dry food
- Dry or sticky tissues in the mouth that make it hard to talk
- Dry skin, skin that "tents" (stays up) when lightly pinched
- A swollen, cracked, or dry tongue
- Fever (See the section called "Fever.")
- Weight loss (See the section called "Weight changes.")
- Little or no urine
- Fatigue (See the section called "Fatigue.")
- Sunken eyeballs

## What the patient can do

- Drink fluids. Sometimes iced fluids are easier.
- Remember that food contains fluid. Try to eat fruits, vegetables, soups, gelatins, Popsicles, and other moist foods.
- Apply lotion often to soften dry skin.
- Try to get rid of the cause of dehydration, such as vomiting, diarrhea, or fever. (See the related sections for information on these causes.)
- Apply lubricant to lips to avoid painful cracking.
- If it is tiring to get up, fill a small cooler with ice and small cans of juice or bottled water and keep it next to you.

- Use ice chips to relieve dry mouth if you can't drink enough liquid.

## What caregivers can do

- Offer cold or cool liquids every hour or so.
- Encourage the patient to eat small meals if he is able.
- Include moist foods, soups, and fruit smoothies (made with ice in a blender) as snacks.
- Watch the patient's urine output to see if it gets dark or the patient stops urinating.
- Check with the patient often to be sure that he hasn't become confused.
- Stand nearby when he gets up, in case of dizziness or fainting.

## Call the doctor if the patient:

- Has vomiting, diarrhea, or fever that lasts for more than 24 hours
- Has urine that is either very dark or only comes in a small amount, or if there is no urine for 12 hours or more
- Becomes dizzy or feels faint when standing up
- Becomes disoriented or confused

## Grooming and appearance

Caring for your appearance can help you feel better about yourself. It is especially important when you are ill, because it can be harder to feel good about yourself when you are sick.

In addition to routine hygiene, you may want to put extra time and energy into the way you look. Looking your best can help you feel more confident and in control.

## What the patient can do

- Keep up with your regular grooming habits, such as shaving, putting on make-up, and fixing your hair, even if you are confined to bed.
- If you will need a wig or toupee, see the section called "Hair loss."
- Have your clothes altered if you lose or gain weight.
- Pamper yourself. Have a manicure or pedicure, a facial, a massage, or something else that makes you feel good. (Check with your doctor or nurse first.)

- Use an electric razor for routine shaving to prevent nicks and cuts.
- Exercise each day, but only as much as you can manage comfortably. Ask your doctor or nurse about an exercise plan, or just take slow, easy walks. (See the section called "Exercise.")
- Get enough rest.
- Keep up with regular dental care.

## What caregivers can do

- When the patient is strong enough, encourage short outings that he can enjoy.
- Help the patient keep a supply of his preferred toiletries, lotions, and grooming supplies on hand.

## Hair loss

The normal scalp contains about 100,000 hairs. They are constantly growing, with old hairs falling out and being replaced by new ones. Some cancer treatments will cause people to lose some or all of their hair, most often in clumps during shampooing or brushing. Sometimes, clumps of hair are found on the pillow in the morning.

It is normal for men and women to feel upset about hair loss. It helps to understand why it happens, to know that hair will grow back, and to take steps to make it less of a problem for you.

Hair loss can happen when chemotherapy drugs travel throughout the body to kill cancer cells. Some of these drugs damage hair follicles, causing the hair to fall out. Hair loss can be hard to predict. Some patients have it, and others do not, even when they take the same drugs. Some drugs can cause hair loss on the scalp and the loss of pubic hair, arm and leg hair, eyebrows, and eyelashes. Some drugs can cause only the loss of head hair. Radiation therapy to the head often causes scalp hair loss. Sometimes, depending on the dose of radiation to the head, the hair does not grow back the same as it was before.

If hair loss does occur, it most often begins within 2 weeks of the start of treatment and gets worse 1 to 2 months after starting therapy. Your scalp may feel very sensitive to washing, combing, or brushing during the short time when your hair is actually falling out. Hair often starts to grow back even before therapy is completed.

## What the patient can do

- If you think you might want a wig, buy it before treatment begins or at the very start of treatment. Ask if the wig can be adjusted – your wig size can shrink as you lose hair.

- If you buy a wig before hair loss begins, the wig shop can better match your hair color and texture. Or you can cut a swatch of hair from the top front of your head, where hair is lightest, to use for matching.
- Be sure to get a prescription from your doctor for the wig because it may be covered by insurance.
- Get a list of wig shops in your area from your doctor, nurse, other patients, or from the phone book. You can also order a "tlc"<sup>TM</sup> catalog (for women with hair loss due to cancer treatment) by calling 1-800-850-9445 or by visiting [www.tlcdirect.org](http://www.tlcdirect.org).
- If you are going to buy a wig, try on different styles until you find one that you really like. Consider buying 2 wigs, one for everyday use and one for special occasions.
- Synthetic wigs need less styling than human hair wigs. They may be easier to care for if you have low energy during cancer treatment.
- Some people find wigs to be hot or itchy. In that case, turbans or scarves can be used instead of wigs. Cotton items tend to stay on your smooth scalp better than nylon or polyester.
- Be gentle when brushing and washing your hair.
- Wear a hat or scarf outdoors in cold weather to reduce the loss of body heat.
- Use sunscreen, sunblock, or a hat to protect your scalp from the sun.
- Hair loss can be somewhat reduced by avoiding too much brushing or pulling of hair and by avoiding heat (such as electric rollers, hair dryers, and curling irons).
- Wear a hair net at night, or sleep on a satin pillowcase to keep hair from coming out in clumps.
- Avoid styles that pull on the hair, such as braids or ponytails.
- Use a wide-toothed comb.
- Be gentle with eyelashes and eyebrows, which are sometimes affected, too.
- If you are bothered by hair falling out, you may choose to cut your hair very short or even shave your head.
- When new hair starts to grow, it may break easily at first. Avoid perms for the first few months. Keep hair short and easy to style.

## Hiccups

Hiccups happen when the diaphragm (the main muscle used in breathing) suddenly contracts between normal breaths. Hiccups can be caused by irritation of the nerve that controls the diaphragm, certain drugs, problems in the brain, problems in the esophagus

(the swallowing tube that goes from the throat to the stomach), pressure on the stomach, and other conditions. Hiccups that last a long time can be serious. They can interfere with eating, sleeping, and breathing, and lead to exhaustion.

## What the patient can do

- Breathe slowly and deeply into a paper bag for 10 breaths at a time.
- Drink water slowly.
- Hold a teaspoon of sugar in the mouth and then swallow.
- Avoid forcing yourself to eat.

## What caregivers can do

- Watch the patient to be sure that he is able to drink enough liquids.
- If medicine is given for hiccups, watch for dizziness. The patient may need help getting up or walking.

### **Call the doctor if the patient:**

- Has trouble breathing
- Develops a puffy or bloated stomach
- Has hiccups that last for more than a day

## Infection

Please see the section called "Fever."

## Itching

Itching can cause restlessness, anxiety, skin sores, and infection. Common causes of itching in people with cancer include dry skin, changes in the blood, allergies, side effects of medicines, and chemo or radiation therapy. Other illnesses and certain kinds of cancer can also cause itching.

### What to look for

- Dry, red, rough, flaky skin
- A yellow color of the skin or of the whites of eyes

- Rash or bumps
- Scratch marks
- Skin sores
- Scratching without thinking about it

## What the patient can do

### **To soothe the skin:**

- Apply skin creams with a water-soluble base, such as aloe vera or menthol-based lotion, 2 to 3 times a day, especially after a bath when the skin is damp. Or use calamine lotion (Caladryl<sup>®</sup>) or witch hazel if they soothe the itching, but note that they can cause dryness.
- Use warm water for bathing instead of hot water.
- Add baking soda, oatmeal (in a cloth or mesh bag), or bath oil to bath water.
- Wash your skin gently using a mild, unscented soap.
- Use baking soda instead of deodorant.
- Avoid using scented or alcohol-based products on the skin (such as powders, aftershave, perfumes). Cornstarch-based powders may clump in moist areas and cause irritation.
- Use an electric razor rather than a blade to avoid cuts and irritation.
- Change your bed sheets daily.
- Keep your room cool (60° to 70° F) and well ventilated to avoid sweating.
- Drink plenty of water and other fluids.
- Get enough rest.

### **To reduce the desire to scratch:**

- Apply cool, wet packs (crushed ice in a plastic bag that is then wrapped in a towel) to the skin. Remove the pack when it becomes warm, and let your skin dry. Use again as needed.
- Keep nails clean and short. Wear clean fabric gloves if you scratch without thinking about it.
- Try rubbing, pressure, cool cloths, or vibration instead of scratching. Avoid breaking the skin. Get gentle massages at night.

- Wear loose clothing made of a soft fabric.
- Distract yourself with music, reading, and the company of others.
- Take medicines for itching as prescribed by your doctor.

## What caregivers can do

- Try using mild, unscented detergents to wash the patient's clothes and bedding.
- If the patient scratches in his sleep, ask him to wear clean cotton gloves which may reduce skin damage.

## Call the doctor if the patient:

- Has itching that does not go away after 2 or more days
- Develops a yellowish color of the skin or has urine the color of tea
- Scratches skin until it is open or bleeding
- Has a rash that gets worse after creams or ointments have been applied
- Has foul-smelling drainage or has pus coming from the skin
- Becomes very anxious and restless (cannot sleep through the night due to itching)
- Develops hives (itchy white or red welts on the skin), shortness of breath, swelling of the throat or face, or other symptoms of a severe allergic reaction

## Leg cramps

Leg cramps or spasms are a painful tightening of the muscles in the leg. Staying in bed for long periods of time sometimes can cause muscles in the leg or foot to cramp. Dehydration, certain drugs, and brain or nerve diseases can also cause cramps. Other causes of cramping are pressure on the calf muscles or on the back of the knee, too much phosphorus, too little calcium, low blood sugar, or too little potassium in the body. All of these are chemistry imbalances in the blood.

## What to look for

- Sudden pain or discomfort in a leg or foot and a tight or stiff feeling
- Trouble moving the foot or pain when moving the foot or leg

## What the patient can do

- Change position often.
- If you are bed-bound, use a bed cradle to protect the legs and feet from the weight of the bed clothes. A bed cradle is a support at the end of the bed that holds the sheets and blanket up off the legs and feet.
- Exercise your legs in bed by bending and straightening them 10 times twice a day or as many times as you can. A family member can move your legs for you if you can't.
- Tell your doctor or nurse about the cramps. They may be able to help prevent them. For example, they may prescribe a muscle relaxant.
- Apply heat to legs when they cramp if it's allowed by your doctor. Talk to your doctor or nurse about what kind of heat to use and how long you should use it.
- Massage the leg if allowed by your doctor.
- Keep warm.
- Contract the opposite muscle group to stretch the tight muscle as much as you can without hurting it. For example, for a calf muscle cramp, try pointing the toes upward toward the knees, or walk around.
- Follow your doctor's instructions for correcting imbalances in calcium, potassium, or phosphorus.

## What caregivers can do

- Help the patient stretch the tight muscle if he can't.
- Use ice or a cold washcloth to gently rub the cramped muscle.
- If muscle relaxers are prescribed, watch for dizziness or stumbling.

### **Call the doctor if the patient:**

- Has cramping that is not relieved by heat, massage, or by stretching the cramped muscle (as described above)
- Has cramping that lasts for more than 6 to 8 hours
- Has a cramped leg that becomes red, swollen, or hot

## Mouth, bleeding in

Bleeding in the mouth is generally caused by mouth sores, gum (periodontal) disease, or by a low platelet count (cells that help the blood to clot). Low platelet counts can be a

side effect of chemo or radiation treatment. This is usually a short-term problem. Cancers that affect the blood-forming system, such as leukemia, can also cause a drop in platelets. A person with low platelets may bleed easily. Everyday actions such as brushing or flossing teeth can cause bleeding (if platelet count is low, see the section called "Blood counts"). Side effects of chemo or radiation can include dryness in the mouth or small mouth ulcers, which can bleed.

## What to look for

- Blood or bruises in mouth (from or on the gums, tongue, etc.)
- Rash or bright red pinpoint-sized dots on tongue, under tongue, on roof of mouth, and/or on inside of cheeks
- Oozing of blood from mouth

## What the patient can do

- Rinse your mouth gently with ice water every 2 hours.
- Have ice chips on hand to suck on. (Avoid hard candies if your mouth is bleeding.)
- Rinse your mouth or brush your teeth with a soft toothbrush after eating. Rinse the toothbrush in warm water to soften the bristles even more.
- Use soft foam mouth swabs or gauze wrapped around a Popsicle stick or tongue depressor to brush teeth if a soft toothbrush causes bleeding.
- Avoid store-bought mouthwash. See the section called "Mouth dryness" to learn how to make a gentle mouth rinse.
- Eat foods that are soft and smooth in consistency and high in calories and protein. Refrigerated soft foods, such as ice cream, applesauce, puddings, and yogurt, are helpful because cold helps to control bleeding.
- Put hard foods, such as apples, pears, etc., in the blender.
- Avoid hot drinks, such as coffee and tea. Heat enlarges blood vessels and can worsen bleeding.
- Apply cream or salve to lips to prevent dryness.
- If you wear dentures, keep them out of your mouth, especially if they do not fit well.
- Avoid aspirin products. Check labels of over-the-counter drugs to be sure they don't contain aspirin, or check with your pharmacist.

## What caregivers can do

- Offer the patient cold water mouth rinses before each meal. Keep ice water nearby.
- If the mouth is oozing blood, keep a bowl nearby for spitting out mouth rinses.
- Make milkshakes or smoothies in the blender, and offer other soft frozen treats. Avoid nuts, caramel, and hard coatings.
- Freeze a few wet tea bags, and have the patient press one on any area of bleeding.

## Call the doctor if the patient:

- Is bleeding from the mouth for the first time
- Has bleeding that lasts for more than a half hour
- Vomits blood or material that looks like coffee grounds
- Feels light-headed or dizzy

## Mouth dryness

Dry mouth happens when there is not enough saliva in the mouth. It can be caused by breathing through the mouth, or it may be a side effect of medicine, radiation treatment to the head and neck, or dehydration. (See the section called "Fluids and dehydration.")

## What to look for

- Dried, flaky, whitish saliva in and around the mouth
- Thick saliva that's more like mucus and that sticks to lips when you open your mouth
- Trouble swallowing foods or thick liquids
- Mouth always open to breathe
- Burning tongue
- Debris stuck to teeth, tongue, and gums
- Tongue surface looks ridged or cracked

## What the patient can do

- Rinse your mouth every 2 hours with a salt and soda solution. You can make this solution by adding 1 teaspoon of salt and 1 teaspoon of baking soda to 1 quart of

warm water. Shake the solution before each use, then swish it in the mouth and spit. Do not swallow it.

- Drink liquids with meals to moisten foods and help with swallowing.
- Try ice chips, sugarless hard candies, and sugarless chewing gum.
- Add liquids (such as gravy, sauce, milk, and yogurt) to solid foods.
- Use petroleum jelly, cocoa butter, or a mild lip balm to keep lips moist.
- Use artificial saliva, which is sold at drugstores.
- Avoid hot, spicy, or acidic foods.
- Avoid chewy candies, tough meats, and hard raw fruits or vegetables.
- Avoid alcohol, including that in store-bought mouthwashes.
- Avoid tobacco.

## What caregivers can do

- Offer small, soft meals with extra sauce or dressings for dipping.
- Offer ice cream, gelatin desserts, ice chips, and frozen drinks.
- Help the patient keep track of his fluid intake, and encourage the patient to take in 2 or 3 quarts of liquid each day, if the doctor approves. Ice, ice cream, sherbet, Popsicles, and gelatin count as liquids.

## Call the doctor if the patient:

- Has a dry mouth for more than 3 days
- Is unable to take medicines or swallow pills
- Is unable to drink or eat
- Has dry, cracked lips or mouth sores (See the section called "Mouth sores.")
- Has trouble breathing

## Mouth sores

Mouth sores are like little cuts or ulcers in the mouth. The sores may be very red, or may have small white patches in the middle. They may bleed or become infected. They can appear 1 to 2 weeks after some kinds of chemo. They can also be caused by radiation treatments to the head and neck area, infection, dehydration, poor mouth care, oxygen therapy, alcohol or tobacco, not getting enough vitamins, or lack of protein. Healing may

take 2 to 4 weeks. Mouth sores can be very painful and lead to dehydration, poor eating, and weight loss. (See the section called "Fluids and dehydration.")

## What to look for

- Inside of mouth and gums look red, shiny, or swollen
- Blood in mouth
- Small ulcers or sores in mouth, on gums, or on or under tongue
- A white or yellow film in the mouth or on the tongue
- Soreness or pain in mouth or throat
- Feeling of dryness, mild burning, or pain when eating hot and cold foods
- Soft, whitish patches or pus in the mouth
- Increased mucus in the mouth

## What the patient can do

- Check mouth twice a day using a small flashlight and a padded Popsicle stick. If you wear dentures, take them out before you inspect your mouth. Tell your doctor or nurse if your mouth looks or feels different or if you notice changes in how things taste.
- Follow the plan below for mouth care 30 minutes after eating and every 4 hours while awake, or at least twice a day unless your doctor or nurse gives you other instructions:
  - 5) Brush your teeth using a soft nylon bristle toothbrush. To soften the bristles even more, soak the brush in hot water before brushing and rinse brush with hot water during brushing. If the toothbrush hurts, use a Popsicle stick with gauze wrapped around it or a cotton swab instead. Or you can get soft foam mouth swabs from the drugstore.
  - 6) Rinse toothbrush well in hot water after use and store in a cool, dry place.
  - 7) Use a non-abrasive toothpaste that contains fluoride. Note that whitening toothpastes may contain hydrogen peroxide, which can irritate sore mouths.
  - 8) Remove and clean your dentures between meals on a regular time schedule. If you have sores under your dentures, leave your dentures out between meals and at night.
  - 9) Clean dentures well between uses, and store them in an anti-bacterial soak. If your dentures fit poorly, do not use them during treatment.

- Gently rinse your mouth before and after meals and at bedtime with one of the following solutions (Stir or shake the solution well, then swish it around and gently gargle, then spit it out.):

1 teaspoon baking soda

2 cups water

**or**

1 teaspoon salt

1 teaspoon baking soda

1 quart water

- If you normally floss, keep flossing at least once a day unless you are told not to do so. Tell your doctor if this causes bleeding or other problems. If you do not usually floss, talk with your doctor before you start.
- Avoid store-bought mouthwashes, which often contain alcohol or other irritants.
- Keep lips moist with petroleum jelly, a mild lip balm, or cocoa butter.
- Drink at least 2 to 3 quarts of fluids each day, if your doctor approves.
- If mouth pain is severe or makes it hard to eat, ask your doctor about medicine that can be swished 15-20 minutes before meals or painted on a painful sore with a cotton swab before meals. If this does not work, you may need stronger pain medicines.
- To promote healing, ask your doctor about using Maalox<sup>®</sup> or Milk of Magnesia<sup>®</sup>. You can use these products to help sores by allowing them to settle and separate, pouring the liquid off the top of the solution, and then swabbing the pasty part onto the sore area with a cotton swab. Rinse your mouth with water after 15-20 minutes.
- Sip warm tea slowly.
- Eat chilled foods and fluids (for instance, Popsicles, ice cubes, frozen yogurt, sherbet, or ice cream).
- Eat soft foods that are moist and easy to swallow.
- Eat small, frequent meals of bland, moist, non-spicy foods. Avoid raw vegetables and fruits, and other hard, dry, or crusty foods, such as chips or pretzels.
- Avoid very salty or high-sugar foods.
- Avoid acidic fruits and juices, such as tomato, orange, grapefruit, lime, or lemon.
- Avoid fizzy drinks, alcohol, and tobacco.
- Create a pleasant mealtime atmosphere.

## What caregivers can do

- Use a flashlight to check the patient's mouth for red areas or white patches, which often become sores. If patient wears dentures, remove them before looking.
- Offer liquids with a straw, which may help bypass the sore area in the mouth.
- Mash or puree hard foods in a blender to make them easier to eat.
- Try coating mouth sores with Anbesol<sup>®</sup> before meals to numb the sores during eating.
- Offer pain medicines a half hour before mealtime.

### **Call the doctor if the patient:**

- Has redness or shininess in mouth that lasts for more than 48 hours
- Has bleeding gums
- Notices any type of "cut" or sore in the mouth
- Has a temperature of 100.5° F or higher when taken by mouth
- Has white patches on the tongue or inside the mouth
- Has taken in little food or fluid for 2 days
- Cannot take medicines due to sores in mouth

## Nausea and vomiting

Nausea is having a sick or queasy feeling in the stomach, and vomiting is throwing up food or liquids from the stomach. Nausea can occur even when a person is not thinking about food. A person can vomit even if he has not eaten anything and hasn't had any nausea. Nausea or vomiting can be caused by eating something that disagrees with you, bacteria in food, infections, or by radiation or chemo treatments for cancer. Many people have little or no nausea and vomiting with these treatments. For others, just thinking about going for one of the treatments can cause nausea or vomiting. Cancer by itself may cause nausea and vomiting.

Frequent vomiting can be dangerous because it can lead to dehydration. (See the section called "Fluids and dehydration.") It can also cause choking or inhaling food or liquids. Talk with your doctor about what is causing your nausea and vomiting and what you can do about it.

### What to look for

- Changes in eating habits

- Foul mouth odor
- Yellow or green foul-smelling fluids on bedclothes
- Feeling queasy or having an upset stomach
- Increased saliva, clamminess, and sweating that may come before vomiting

## What the patient can do

### **For nausea:**

- Eat bland foods, such as dry toast and crackers.
- If the nausea only happens between meals, eat frequent, small meals and have a snack at bedtime.
- Drink clear liquids served cold and sipped slowly. (Clear liquids are those that you can see through, such as ginger ale, apple juice, broth, tea, etc.) Also try Popsicles or gelatin.
- Seek out the foods you like. Many people develop a dislike for red meat and meat broths during treatment. Try other protein sources, such as fish, chicken, beans, and nuts.
- Suck on hard candy with pleasant smells, such as lemon drops or mints, to help get rid of bad tastes.
- Eat food cold or at room temperature to decrease its smell and taste. Avoid fatty, fried, spicy, or very sweet foods.
- Try small amounts of foods high in calories that are easy to eat (such as pudding, ice cream, sherbets, yogurt, and milkshakes) several times a day. Use butter, oils, syrups, sauces, and milk in foods to raise calories. Avoid low-fat foods unless fats upset your stomach or cause other problems.
- Tart or sour foods may be easier to keep down (unless you have mouth sores).
- Try to rest quietly while sitting upright for at least an hour after each meal.
- Distract yourself with soft music, a favorite television program, or the company of others.
- If you have nausea, relax and take slow, deep breaths.
- Tell your doctor about the nausea because there are several drugs that can help it.
- Take your anti-nausea medicine at the first signs of nausea to help prevent vomiting.

- If nausea occurs just before chemo or doctor visits, ask about medicines, hypnosis, relaxation, or behavioral treatment to lessen this problem.

### **For vomiting:**

- If you are in bed, lie on your side so that you will not inhale the vomit.
- Request that medicines be prescribed in suppository form, if possible. Take medicine at the first hint of nausea to prevent vomiting.
- Try liquids in the form of ice chips or frozen juice chips, which can be taken slowly.
- After vomiting stops, begin by taking in 1 teaspoon of cool liquid every 10 minutes. Gradually increase to 1 tablespoon every half hour. If you are able to keep that down after an hour or so, try larger amounts.

### **What caregivers can do**

- When the patient feels nauseated, offer to make meals or ask others to make meals to reduce bothersome food odors. Use kitchen vent fans to reduce smells.
- Cover or remove foods with strong or unpleasant smells.
- Try plastic forks and spoons rather than metal ones, which may cause a bitter taste.
- If the patient starts vomiting, weigh him at the same time each day to help decide whether dehydration is getting severe.
- Talk to the doctor about medicines to help prevent vomiting.
- Watch the patient for dizziness, weakness, or confusion.
- Try to help the patient avoid constipation and dehydration. Either of these can make nausea worse.

### **Call the doctor if the patient:**

- May have inhaled some of the vomited material
- Vomits more than 3 times an hour for 3 or more hours
- Vomits blood or material that looks like coffee grounds
- Cannot take in more than 4 cups of liquid or ice chips in a day or cannot eat substantial foods for more than 2 days
- Cannot take his medicines
- Becomes weak, dizzy, or confused

- Loses 2 or more pounds in 1 to 2 days (This means he is losing too much water.)
- Develops dark yellow urine and doesn't have to urinate as often as usual

## Pain

When people say they are having pain, it usually means they are hurting somewhere in their body. But it can also mean that they just can't get comfortable. They may be feeling bad in general, not in any one place. The feeling of pain can be worse if a person is anxious, sad, or depressed. Some people may have a hard time talking about their pain. This may be because of the way they were brought up, the way people in their family usually express themselves, or just because that's the way they are. In general, the way they talked about pain in the past, before the illness, will be the way they talk about it now.

Even severe pain can be very well controlled by combinations of medicines that can be taken by mouth. These combinations usually include opioids (OH-pee-oyds), such as morphine or codeine. Some people may not want to use these pain medicines because they fear they will become addicted. But people with cancer who have never abused drugs do not become addicted or use the opioid pain-relieving drugs for pleasure. Their bodies can become tolerant of the pain medicine after a time, so the dose may need to be increased to get the same pain relief. This is a common sign of opioid tolerance. But when the person has cancer pain, it is not a sign of addiction.

Pain medicines work best if they are used around the clock before the pain becomes severe. It takes more medicine to control severe pain than milder pain, so it's best to treat it when it first starts and regularly after that. If the cause of the pain is treated, the need for medicine will slowly decrease or disappear. Drug dosage and schedule should be adjusted by the doctor as the patient's needs change.

If you have pain from cancer that has spread, or some other long-term cancer pain, it can exhaust you. This type of chronic or long-term pain can interfere with your life and keep you from doing things that you want and need to do. Even with around-the-clock pain medicines, pain often "breaks through" between doses. Breakthrough pain usually calls for a second pain medicine that you can safely take in addition to your regular pain medicine. Don't be surprised if it takes more than 2 medicines to control your pain. Help your doctor keep your pain under control by taking pain medicines as prescribed, and keeping your doctor informed about your level of pain.

## What to look for

- Pain that doesn't seem to go away or that seems to go away, then comes back before your next dose of medicine is due (This may indicate that your medicine plan needs to be changed.)
- Trouble sleeping

- Lack of interest in things you used to enjoy
- Worry about things that had not caused concern in the past
- New areas of pain or a change in your pain
- Reduced ability to move around or less physical activity

## What the patient can do

- Talk with your doctor or nurse about your pain – where the pain is, when it began, how long it lasts, what it feels like, what makes it better, what makes it worse, and how it affects your life.
- If the prescribed pain medicines don't work as expected, let your doctor or nurse know.
- Rate your pain using a pain rating scale, such as 0 = no pain to 10 = the worst pain you can imagine. You can use this scale to explain your pain to others.
- Take your pain medicine exactly as prescribed. (For chronic pain, medicine should be given around the clock on a schedule rather than only when pain is severe.) Check with your doctor if this schedule needs to be adjusted.
- As the pain is relieved with medicines, increase your activity level.
- Do not wait until the pain is severe before taking pain medicine.
- Avoid suddenly stopping any of your pain medicines. Instead, reduce the dosage slowly as the pain decreases. Talk with your doctor, nurse, or pharmacist before you do this, or if you have questions.
- Some people feel nauseated even when they are taking the right dose of pain medicine. If your pain medicine makes you feel sick, ask your doctor to change it or to give you something to control the nausea.
- Some pain medicines make you drowsy or dizzy. This often lessens after a few days, but you may need help getting up or walking. Don't try to drive or do anything dangerous until you are sure of the effects.
- People taking opioid pain medicines are normally given laxatives and stool softeners to prevent constipation, which is a common side effect of opioids.
- Keep track of any other side effects you notice. Discuss them with your doctor or nurse.
- Avoid crushing or breaking your pain pills unless you check with your doctor, nurse, or pharmacist. If medicines are in time-release form, taking broken pills can be dangerous.

- If pain medicines are not keeping your pain under control, talk with the doctor about other measures. If you keep having trouble, ask to see a pain specialist.
- Keep at least a one-week supply of pain medicines on hand. Most pain medicines cannot be refilled by telephone, so you will need a written prescription.

## What caregivers can do

- Watch the patient for signs of unrelieved pain. Ask the patient about pain if you notice grimacing, moaning, tension, or reluctance to move around in bed.
- Try warm baths or warm washcloths on painful areas. (Avoid areas where radiation was given.) If this doesn't help, you can try ice or cool packs. Gentle massage or pressure may help some types of pain.
- Watch for confusion and dizziness, especially after new medicines are started or when doses are changed. Help the patient with walking until you know he can do it safely.
- Encourage pleasant distractions that the patient enjoys.
- Plan activities for when the patient is most comfortable and awake.
- Offer plenty of fluids and food with fiber.
- If the patient seems forgetful, help him track when pain medicines are due to avoid over- or under-dosing.
- Help the patient remember to take stool softeners and laxatives the doctor suggests to prevent constipation. (See the section called "Constipation.")
- If the patient is having frequent, severe pain, talk with the doctor about medicine to take around the clock. If pain "breaks through," find out if there is another medicine to use between doses of the main pain medicine.
- If the patient is having trouble taking pills, talk with the doctor about medicines that come in liquids, suppositories, skin patches, or other forms.
- Check with the doctor, nurse, or pharmacist before you crush or dissolve pain pills to make them easier to swallow. Some pills can cause a dangerous overdose if broken.
- Remind the patient that pain medicine, when used as directed, does not cause addiction.
- Talk with the doctor or nurse so that you understand which medicines are for pain and how each is to be used.
- Be sure that the patient has a list of all the medicines he is on, including pain medicines. This is even more important if unexpected medical problems come up.

- Know how to reach the doctor when his office is closed.
- Plan time for activities you enjoy and take care of yourself. A support group for family members may be helpful.
- If you help the patient with pain patches, be sure you know how to avoid touching the part with the pain medicine on it, and how to dispose of used patches safely.
- Keep opioid pain medicines away from others, especially children and pets.

### **Call the doctor if the patient:**

- Has any new or more severe pain
- Cannot take anything by mouth, including the pain medicine
- Does not get pain relief, or if the relief doesn't last long enough with the medicines that have been prescribed
- Has trouble waking up, or if you have trouble keeping him awake
- Becomes constipated, nauseated, or confused
- Has any questions about how to take the medicines
- Develops a new symptom (for instance, is unable to walk, eat, or urinate)

For more in-depth information on pain management, call the American Cancer Society at 1-800-227-2345. You may want to ask for a copy of *Pain Control: A Guide for Those With Cancer and Their Loved Ones*. You can also find pain information on our Web site.

## **Prostheses**

Prostheses (pross-THÉE-sees) are man-made substitutes for missing body parts. Sometimes, parts of the body must be removed if they contain cancer that could grow and spread. Prostheses are used to help a person look as though the body part had never been removed, and to help the person function as normally as possible.

There are many different types of prostheses. Some are external (worn on the outside) and can be put on and taken off, and others are implanted during surgery. Those most commonly needed by people with cancer are prostheses for the breast, leg, or testicles and penile implants. Wigs used to cover the short-term hair loss that may happen with some kinds of chemo can also be considered prostheses. (See the section called "Hair loss.")

### **What the patient can do**

- Before surgery, ask your doctor about prostheses.

- Find out if you might need a prosthesis. If so, ask if the prosthesis can be placed or implanted during surgery. (Prostheses for testicles, breasts, and some limbs may be implanted during the first surgery.)
- Make sure that you get a prescription for the prosthesis from your doctor, because it may be covered by medical insurance (this includes wigs).

### **Breast prostheses:**

- Contact your local chapter of the American Cancer Society Reach To Recovery<sup>®</sup>, a support group for women with breast cancer, for information and ideas.
- Wear a breast form (external prosthesis) while waiting for reconstructive surgery.
- Small prostheses ("equalizers") are available for women who have had part of a breast removed (through lumpectomy or a segmental mastectomy).
- Nipple prostheses are available for breast reconstruction when the nipple cannot be saved. External nipple prostheses are also sold to cover flat or missing nipples.
- External prostheses are sold in surgical supply stores, lingerie shops, and in the lingerie departments of many department stores. Call before you go to make sure that a professional fitter will be there.
- Wear a form-fitting top when you shop for a prosthesis, so that you can better see how it looks when you move.
- Have your partner or a good friend go with you.
- Try many different types. Prostheses vary in shape, weight, and consistency. Custom-made forms are also available.
- Shop around; find the best fit and the right price.
- Prostheses may feel heavy, but they should feel comfortable, show natural contour and consistency, and stay in place when you move.
- Ask if the prosthesis absorbs perspiration and how to care for it.
- Talk with your partner about your feelings about reconstructive surgery and changes in your body.
- See the section called "Sexuality" for more information.

### **Leg or limb prostheses:**

- Before surgery, ask about your options, including when and how your prosthesis will be fitted.

- Often, a temporary leg prosthesis is fitted during the first surgery. Put your weight on it as advised by your doctor or physical therapist. The permanent prosthesis can be fitted after you are stronger.
- Cosmetic, non-functional (non-working) limbs are available for people who cannot use a permanent prosthesis.
- Ask questions about how to care for the surgical site and the prosthesis. If you have discomfort, redness, or blisters, talk with your doctor. If the prosthesis needs to be adjusted, take it back to a professional rather than trying to do it yourself.

### **Testicular prostheses:**

- A gel-filled plastic sac can be placed during surgery or at a later date.
- Not all men want or feel that they need a testicular prosthesis. Discuss the possibility of a prosthesis with your partner.
- Before surgery, talk with your doctor about whether you want testicular prostheses.
- See the section called "Sexuality" for more information.

### **Penile implants:**

- Penile implants or prostheses are placed 6 to 12 months after surgery.
- Two different types are available: inflatable and semi-rigid rod. Discuss the type that is best for you with your partner and your doctor. See the section called "Sexuality" for more information.

### **Call the doctor if the patient:**

- Develops redness, swelling, pain, pus, or drainage at the prosthesis site

## **Scars and wounds**

A wound is a physical injury to the body that causes disruption in body structure. The wound may be present only under the skin, may affect only the skin surface, or may involve both. An incision from surgery is a wound. A wound also can be caused by a fall or accident, tumor growth, pressure on bony areas, or the side effects of radiation therapy. Proper care for a wound is important to protect the wound from infection and help it heal. Scars are healed wounds.

### **What to look for**

- Redness or purple bruising of skin

- Scaly, broken skin (See the section called "Skin (pressure) sores.")
- Crusts, scabs, or cuts in the skin
- Drainage or pus
- Bleeding
- Swelling
- Warmth or heat at the affected area
- Pain

## What the patient can do

- Wash your hands well before and after changing wound dressing. Never re-use dressings.
- Always keep the wound clean. Unless you were given different instructions, clean the wound every day with soap and water, rinse well, and pat it dry with a clean towel.
- Dress wounds as instructed by the doctor or nurse, or use sterile, non-stick gauze. If possible, use paper tape.
- Keep your dressing clean and dry. If it gets wet or dirty, change it right away.
- If the wound is bleeding, clean it well and apply moderate pressure with a cool cloth or ice pack until the bleeding stops. Then continue with dressing change.
- If possible, do not place tape directly on skin. (Use a "skin prep" solution, or wrap gauze over the bandage and then tape the gauze. Check with your nurse or pharmacist about supplies.)
- Avoid scratching or rubbing the wound or removing scabs.
- Eat citrus fruits, green leafy vegetables, whole grains, meat, fish, and eggs. They contain vitamins and minerals that help promote wound healing.

## What caregivers can do

- Help clean wounds or change dressings if the patient is unable to do it for himself. If you can, wear a fresh pair of disposable plastic gloves each time you clean the area and put on a new dressing. Wash your hands before and after changing a dressing, even if you wear gloves.
- Be sure the patient has enough supplies to change the dressing as often as you were instructed.
- Check for signs of infection.

## **Call the doctor if the patient:**

- Has a wound that bleeds for 15 minutes or more
- Has a wound that looks very red around the edges and is hot or swollen
- Has more pain than usual at the wound site
- Develops a bad smell from the wound
- Has yellow pus or greenish liquid that oozes from the wound
- Has a fever of 100.5° F or higher when taken by mouth

## **Seizures**

A seizure is the uncontrolled movement of muscles. It happens when nerve cells in the brain become overexcited and do not work properly. Seizures usually last less than 5 minutes. They are followed by a period of sleepiness and confusion, which can last for several hours. Seizures in cancer patients can be caused by high fevers, head injury, serious infections of the fluid around the spine and brain, an imbalance in body chemistry, and tumor growth in the spine or brain.

### **What to look for**

- Eyes stare blankly or roll back
- Patient suddenly loses control of urine and bowels
- Jerking movements of the body, especially the arms and legs

### **What the patient can do**

- Talk to the doctor about your seizures. Bring the person who saw your seizure to the doctor with you to answer the doctor's questions about it.
- Take anti-seizure medicines as prescribed.

### **What caregivers can do**

- Keep the patient safe. If a seizure starts while the patient is in bed or on a chair, cradle the patient in your arms to keep him from falling to the floor.
- Stay with the patient.
- Stay calm.
- Loosen any clothing around the patient's neck.

- If the patient falls to the floor, place padding (such as rolled-up clothes or towels) under his head and roll him onto his left side.
- If the patient is lying on his back, gently turn the head to the side if possible. Do not move any part of the body forcefully.
- Try to notice what type of movements the patient makes, how long the seizure lasts, and which parts of the body move with the seizure.
- Do not try to open the mouth during a seizure, even if the patient is biting his tongue. Keep your fingers and hands away from the patient's mouth.
- Do not move the patient unless he is in a dangerous location (for instance, near a hot radiator, glass door, or stairs).
- Once the seizure is over, cover the patient with a blanket and allow him to rest.
- Do not give medicines, food, or liquids until you call the doctor and the patient is fully awake.
- If the patient is prone to seizures, use side rails and bumper pads on his bed. Be sure someone is with the patient when he is walking or sitting in a chair.
- Give anti-seizure medicine as prescribed by the doctor.

### **Call the doctor if the patient:**

- Has a seizure, once it is over and the patient is comfortable (If someone else is with you, stay with the patient and have the other person call the doctor.)

## **Sexuality**

Sexuality includes all the feelings and actions associated with loving someone. It includes holding hands, special looks, hugging, kissing, etc. It is not just the act of sex. This section addresses side effects of different treatments that affect your sex life and ways to relieve some common problems. It is important that you talk about any questions or concerns with your doctor or nurse, and most importantly, with your partner. Remember that warmth, caring, physical closeness, and emotional intimacy are as necessary and rewarding as any other kind of human interaction.

Cancer treatment often affects the ability of men or women to have children. Chemo, radiation, and some surgery can affect the reproductive system and cause infertility. In women, treatment may cause early menopause. It is hard to predict the outcome for any one person. Some people are still fertile after treatment; others are not.

Chemo and radiation can also cause birth defects if a child is conceived during treatment or within several weeks of ending treatment. Avoid pregnancy during chemo or radiation. Find out if there is a period of time you should wait after your specific type of treatment

before trying to conceive. Talk with your doctor about what to expect, and about any plans to have children. Do this *before* treatment begins.

## What the patient can do

- Realize that your sexual desire may decrease due to the fear of having cancer and treatment, as well as because of treatment itself. Chemo can make you very tired or sick. Radiation therapy to the pelvis or genital area can sometimes cause pain during sex. Hormone treatment and the removal of the ovaries or testicles will change your body's hormone levels. All of these things can affect sexual desire.
- Talk with your partner about your feelings and concerns.
- Wait until you feel ready for sexual activity. Do not push yourself.
- Express desire for sexual contact when you feel able; do not wait for your partner to ask.
- Avoid sex if your white blood counts are dangerously low to reduce your chance of infection. (See the section called "Blood counts" for more information.) Check with your doctor to see if this is an issue for you.
- Enjoy other forms of closeness, such as touching, caressing, and holding each other.
- If you've had major surgery, ask your doctor if implants or reconstructive surgery is possible.
- Understand that you cannot give your partner cancer.
- Try other things if your usual sexual activities are uncomfortable, such as:
  - 10) Manual stimulation (using hands)
  - 11) Oral-genital stimulation
  - 12) Caressing, fondling, kissing
  - 13) Different positions (for instance, lying on your sides either facing or spooning, or switching who is on top). New positions can allow you to control thrusting, avoid pressure on tender areas, or avoid tiring.

## Men:

- Before you have chemo or radiation to the genital area, ask your doctor about saving sperm in a sperm bank.
- In about 40% to 60% of men, some degree of impotence (inability to get an erection) may slowly develop over 1 or more years after radiation to the genital area. Impotence usually does not happen right after radiation treatment. This is different

from the effects of prostate surgery, which are seen right away and may improve over time.

- Men who have been treated for testicular, prostate, bladder, colorectal, and even head and neck cancers often report having trouble getting erections after treatment.
- Ask your doctor about getting serum testosterone levels checked to see if hormone replacement therapy would help you. Ask about other medicines or treatments that may help you, too.
- Radiation treatment to the genital area can cause pain during ejaculation for a short time. It can also reduce the amount of semen and cause skin irritation.
- Men who have testicular cancer and have lymph nodes removed often have little or no semen at orgasm. (This is called "dry ejaculation.") The return of your semen may take months or years, or may not happen at all. Semen is not needed for your or your partner's satisfaction.
- For men who have prostate cancer, blood in the semen is not unusual during diagnosis or treatment, especially after a needle biopsy. This is not harmful or worrisome, but should be reported to your doctor.
- Sometimes, urination may occur accidentally during sexual activity. There is no need for concern about this. Urine is normally sterile and will not harm your partner.
- Use erotic stimulation, such as romantic dinners and prolonged foreplay.
- Shower together and use sexual play.
- Men with prostate cancer who have had radiation seeds implanted may need to use condoms for a few weeks because the seeds may become dislodged during sexual activity. Ask your doctor how long you will need to use condoms.

## **Women:**

- Pain during sex is very common after surgery for many gynecologic cancers because the treatment may shorten or narrow the vagina. Ask your surgeon about the exact extent of your surgery. To help with this:
  - 14) Use positions that give you control of depth and force of thrusting (for instance, woman on top, or both partners lying on their side).
  - 15) Use your thumb and index finger at the vaginal entrance to circle around the penis. This can provide extra length and keep your partner from thrusting too deeply.
  - 16) Keep the vagina from shrinking and tightening during radiation therapy to the pelvis or vagina. You will need to insert fingers, your partner's penis, or special vaginal dilators (enlargers) 3 to 4 times a week while you get radiation treatment and afterward.

- 17) If surgery that involves the vagina is planned, talk with your doctor or nurse about vaginal dilators to use after surgery. Be sure to find out when to start using them and how.
- 18) Use an unscented, uncolored lubricant such as K-Y Jelly<sup>®</sup> or Astroglide<sup>®</sup> if lubrication becomes a problem. Surgery, radiation, or hormone treatment can cause dryness.
- 19) Show your partner ways of touching or positioning that are comfortable to you, such as between the thighs or buttocks or between the breasts.
- 20) Before you try sex with your partner, check to see if there is any soreness in your genital area.

- Chemo can cause thinning of the vaginal wall. Slight bleeding after sex is not a major concern, but it may help to use extra water-based lubricant. Avoid contraceptive gels, films, or foams, which contain chemicals that can irritate the vagina.
- Chemo can also reduce sexual desire and make it harder to reach orgasm. This usually gets better after treatment is over.
- Burning during sex may suggest a yeast infection. Talk to your doctor if this happens.
- Chemo may cause you to stop menstruating for some time, but may not entirely stop the ovaries from working. It may still be possible to get pregnant even if you haven't menstruated for several months. Talk with your doctor about birth control, since chemo drugs can hurt a growing fetus.
- Chemo, radiation, or surgery that removes the ovaries may cause early menopause. Ask your doctor about your chances of this happening.
- If infertility is likely, talk with your doctor about the possibility of freezing ovarian tissue or eggs. This requires special surgery and is very expensive, but it may be an option for some women.

### **If you have an ostomy:**

- Empty the pouch before sexual activity.
- Ask your enterostomal therapist about a pouch cover that doesn't look "medical."
- If a leak occurs, shower together and continue sexual play.
- Tuck pouch into a supportive belt or cummerbund.
- Turn appliance to the side.
- Try different positions if there is friction.
- For women, try crotchless, lacy underwear or lingerie that covers the appliance, but leaves the genital area open.

- Some people are more comfortable wearing a T-shirt to cover the stoma at first.

## What partners can do

- Find out how cancer and the cancer treatment are likely to affect your sexual relationship. For instance, chemo can cause side effects such as fatigue. Surgery and radiation in the genital area may permanently change the structure and function of the genitals.
- Learn what changes to expect if the person is taking hormones, which may affect sexual function or desire.
- Be patient during chemo or radiation. Wait for times when your partner feels ready for sexual activity.
- Offer physical closeness and touching when the patient's energy is low. Intimacy can be achieved without sex, erections, or orgasms. Kindness, affection, and respect go a long way toward reaching this goal.
- Find out how the patient feels about his body and about sexual activity. Sometimes, people feel unattractive after cancer treatment.
- It is normal to grieve about losses and changes in body image, which affect both of you. Consider talking with a mental health professional if you have had difficult changes in your relationship.
- When your partner is ready, be willing to try more gentle activities and new positions that feel good to both of you. Plan for private time when you will not be interrupted.
- Use unscented, uncolored water-based lubricant (such as K-Y Jelly or Astroglide) if dryness causes discomfort for either of you.
- If you are afraid of hurting your partner, talk about it with your partner and with the doctor or nurse.

## Call the doctor if the patient:

- Notices new or more pain
- Notices bleeding
- Has a change in erectile function or in the amount of semen
- Has any sexual problems or questions concerning sexual activity

For more in-depth information, contact the American Cancer Society at 1-800-227-2345 and ask for *Sexuality for the Woman With Cancer* or *Sexuality for the Man With Cancer*. You can also find information on our Web site. For questions about fertility options, such as freezing eggs or sperm before chemo, visit [www.fertilehope.org](http://www.fertilehope.org) or call 1-866-965-7205.

# Shortness of breath

If the patient has trouble breathing, the body may not get enough oxygen. Either the lungs cannot take in enough air, or the body cannot get enough oxygen through the bloodstream. A number of different problems can cause this, including chronic lung disorders, blocked airways, pneumonia, weak breathing muscles, or obesity. It can also be caused by pain, immobility, poor nutrition, stress or anxiety, allergic reactions, surgery, anemia, side effects of chemo or radiation treatment, tumor, fluid in the lungs, heart failure, and other problems.

## What to look for

- Shortness of breath or trouble breathing at rest, when eating or talking, or with exercise
- Chest pain
- Faster breathing
- Faster heartbeat
- Pale or bluish-looking skin
- Blue fingernail beds
- Cold and clammy feeling skin
- Nostrils flaring when inhaling
- Wheezing

## What the patient can do

- Stay calm.
- Sit up or raise the upper body to a 45° angle by raising the bed or using pillows.
- Take medicine or treatments prescribed for breathing (for example, oxygen, medicine for relief of wheezing, inhalers, or nebulizers).
- If you are not in a lot of distress, check your temperature and pulse.
- Inhale deeply through your nose and exhale through pursed lips for twice as long as it took to inhale. (This is called pursed-lip breathing.)
- If there is still no relief after 5 minutes, sit up on the side of the bed, with feet resting on a stool, arms resting on an overbed table or side table with pillows on it, and head tilted slightly forward.

- If you are coughing and spitting, note the amount of sputum and what it looks and smells like.
- Talk with your doctor about how your breathing problem affects you, especially if you avoid some of your usual activities to keep from getting out of breath.
- Try muscle relaxation to reduce anxiety. Anxiety makes breathing problems worse.
- If you keep having trouble breathing, ask your doctor about medicines you can use to help.
- If new shortness of breath starts suddenly and does not improve; your skin looks pale or blue; or if you have chest discomfort, trouble speaking, dizziness, or weakness, call 911.

## What caregivers can do

- Use a watch with a second hand to check the patient's pulse, counting the number of beats per minute. (If you count the number of beats per minute, do it without telling the patient. If the patient knows when you are counting, he may slow down or speed up the breathing rate without realizing it.)
- Check the patient's temperature to see if he has a fever.
- If the patient is short of breath, remove or loosen tight clothing.
- Have the patient sit up in a resting position that feels comfortable to him.
- Remind him to take slow, deep breaths, and exhale slowly.
- Remove the patient from extreme temperatures, especially heat, which may make it harder to breathe.
- Note whether the patient gets out of breath when doing strenuous activity, normal activity, or when he is at rest, and whether it happens when the patient is standing, sitting, or lying down.
- Putting the patient in front of an open window or placing a fan that blows gently on the face may help some people.
- Offer any medicines or inhalers prescribed for shortness of breath.
- If home oxygen is prescribed, be sure that you know how to set it up and what flow rate to use. (Do not change the flow rate without first talking to the doctor.) Don't allow smoking or fire when oxygen is in use.

## Call the doctor if the patient:

- Has trouble breathing or chest pain

- Has thick, yellow, green, and/or bloody sputum
- Develops pale or bluish skin or if the skin feels cold and clammy
- Has a fever of 100.5° F when taken by mouth
- Has flared nostrils during breathing
- Becomes confused or restless
- Has trouble speaking
- Has dizziness or weakness
- Has swelling of the face, neck, or arms
- Develops wheezing

## **Skin color changes**

Skin color changes usually happen because there is some type of change in the body. For example, a person may look yellow because of liver problems, blue because of breathing problems, bruised because of blood disorders, or red because of skin problems. Changes in the skin can be due to tumor growth, sun exposure, or the side effects of chemo or radiation therapy. Some color changes may improve over time, while others may be permanent.

### **What to look for**

- Yellowish color to skin and/or whites of eyes
- Deep orange to brown urine
- White or clay-colored (light brown or gray-looking) stools
- Bruises or areas of blue or purple skin that have no known cause
- Trouble breathing (If present, see the section called "Shortness of breath.")
- Redness or rash on skin
- Swelling in an area that is discolored
- Itching (See the section called "Itching.")

### **What the patient can do**

- Clean the area gently with warm water, gentle soap, and a soft cloth.
- Rinse the area carefully and pat dry.

- Apply water-repellent salve, such as petroleum jelly or A & D ointment.
- Wear loose-fitting clothing made of soft fabrics, such as cotton.
- Expose the affected skin to air whenever possible.
- Protect the affected area from heat and cold.
- Keep your skin protected from the sun. (For instance, wear a wide-brimmed hat and long-sleeved shirts when outside.)
- Apply sunscreen with an SPF of 15 or higher to any skin exposed to the sun.
- Apply medicine prescribed for skin reactions.

## What caregivers can do

- Keep track of any new medicines, soaps, detergents, or new foods that may have caused a rash.
- If a patient's hands are affected, do not let the patient do tasks involving hot water.
- Offer gentle massages with moisturizing lotions or creams.

## Call the doctor if the patient:

- Has urine that remains dark or orange for a day or more
- Has stool that looks white or clay colored for 2 or more bowel movements
- Develops a yellowish color on the skin or in the whites of the eyes
- Has severe itching (See the section called "Itching.")
- Has bruises that do not go away within a week, or new bruises that continue to appear for 3 days
- Has red or rash-like areas on the skin

## Skin dryness

Dry skin can be rough, flaky, red, and sometimes painful. It is caused by not enough oil and water in the layers of the skin. Common causes of dry skin include dehydration, heat, cold, poor nutrition, and side effects of radiation treatment or chemo.

## What to look for

- Red, rough, flaky skin (although dry skin can look normal)

- Cracks in the skin
- Slight bleeding between the lines of skin covering body areas, such as knuckles or elbows

## What the patient can do

- Add mineral or baby oil to warm bath water, or apply after showering while skin is still damp. (This can make you slippery, so be careful to keep from falling.)
- Wash with cool or warm water – not hot water.
- Avoid scrubbing during showers or baths. Gently pat skin dry after bathing.
- Apply water-based creams twice a day, especially after baths.
- Avoid colognes, after-shaves, and after-bath splashes that contain alcohol.
- Use an electric razor.
- Drink 2 to 3 quarts of liquid a day if it's OK with your doctor.
- Protect your skin from cold and wind. Avoid hot water and heat, especially dry heat.

## What caregivers can do

- Apply lotions or oils on hard-to-reach places.
- Offer extra fluids.

## Call the doctor if the patient:

- Develops very rough, red, or painful skin
- Has signs of infection, such as pus or tenderness near broken skin

## Skin (pressure) sores

A skin or pressure sore develops when the blood supply to an area of the body is stopped and the skin in that area dies. A person who is bedridden or always in a wheelchair puts pressure on the same places much of the time. This reduces the blood flow to these places, making them more likely to develop open sores. These areas are made worse when the patient rubs against his sheets or is roughly pulled up in the bed or chair.

## What to look for

- Red areas on the skin that do not go away even after the pressure is removed

- Cracked, blistered, scaly, or broken skin
- An open sore involving skin surface or tissue under the skin
- Yellowish stains on clothing, sheets, or chairs (may be tinged with blood)
- Painful or tender "pressure points" (such as on the back of the head, ears, back of shoulders, elbows, buttocks, hips, heels, or any place a bony part rests on the bed surface)

## What the patient can do

- Change position at least every 2 hours from your left side, to your back, to your right side.
- In a wheelchair, shift your weight every 15 minutes. Use special seat cushion to reduce pressure.
- Protect other "pressure points" with pillows to help prevent new sores. If possible, use pressure-reducing mattress or 3- to 4-inch foam layer over your mattress.
- Exercise as much as possible. For example, take a short walk 2 or 3 times a day. If you are not able to walk, pull up, and move your arms and legs up and down and back and forth.
- Eat foods high in protein (such as fish, eggs, meats, milk, or peanut butter).
- Increase fluids. (If you are not eating well, try high-calorie liquids such as milkshakes.)
- Bathe each day, and look at the pressure point areas.
- Always protect the sore and the area around it with a foam wedge or pillow.
- Rinse any open sore with water very carefully and cover with a bandage. Do this every time the bandage gets soiled, or at least twice a day as instructed by your doctor or nurse. If your doctor gives you ointments or creams, use them as prescribed. Report any itching or blistering in the area.

## What caregivers can do

- Remind the patient to change position often, or help the patient turn every 2 hours.
- If the patient cannot control his bowel and bladder, change his underwear as soon as you notice soiling, and then apply an ointment (such as A & D ointment) to keep the area dry. Sprinkle cornstarch over the ointment. Avoid using plastic underwear unless the patient is out of bed. Use underpads to keep the patient from soiling the bed while lying down.

- If the skin is open, talk with the doctor about special dressings to help protect it.
- If the patient is bedridden:
  - 21) Keep the bottom sheets pulled tight to prevent wrinkles.
  - 22) Keep the head of bed flat or at a 30° angle.
  - 23) Sprinkle sheets with cornstarch to reduce friction from rubbing against them.
  - 24) Inspect the patient's back and sides each day to be sure that the skin looks normal. If a reddened "pressure area" (an area that stays red after pressure is taken off it) is noticed, keep the pressure off it as much as possible to try to prevent further breakdown. Use pillows and have the patient change position frequently.
- If the patient has trouble staying on his side, find out about foam wedges to help hold positions.
- Foam pads for the bed and chairs may help some patients.
- If the problem continues, talk to the doctor or nurse about home care options. Find out about special beds that reduce pressure areas.

### **Call the doctor if the patient:**

- Has cracked, blistered, scaly, or broken skin
- Has a sore that is getting larger
- Has a thick or bad-smelling liquid draining from the sore
- Needs a referral to a home care agency for help with pressure sore care and supplies

## **Sleep problems**

Sleep problems can be defined as a change in usual sleeping habits. People who are getting treatment for cancer may get tired more easily and may need to sleep more than usual. Sometimes, the opposite problem occurs and people may have trouble sleeping. Reasons for changes in usual sleeping habits include pain, anxiety, worry, depression (see the related sections), night sweats, or side effects of treatment or prescription drugs.

### **What the patient can do**

- Sleep as much as your body tells you to, but when you are awake, try to exercise at least once a day. Do this at least 2 to 3 hours before bedtime. (See the section called "Exercise.")

- Avoid drinks with caffeine for 6 to 8 hours before bedtime.
- Avoid alcoholic drinks in the late evening. They can keep you awake as they "wear off."
- Drink warm, caffeine-free drinks, such as warm milk with honey or decaf tea, before sleep.
- Use a quiet setting for rest during the same period of time each day.
- Take sleeping medicine or pain relievers prescribed by the doctor at the same time each night. If pain keeps you awake, see the section called "Pain."
- Have someone give you backrubs or massage your feet before bedtime.
- Keep sheets clean, neatly tucked in, and as free from wrinkles as possible.
- Talk with your doctor about relaxation therapy or a referral to a hypnotherapist.

## What caregivers can do

- Help keep the room as quiet and comfortable as possible during sleep times.
- Offer gentle backrubs or foot massages near bedtime.
- Offer a light bedtime snack.
- Let the doctor know if the patient appears to be confused during the night.

## Call the doctor if the patient:

- Is confused at night
- Is unable to sleep at all during the night

## Steroids and hormones

Hormones are natural substances in the body. *Corticosteroids* (or steroids), such as cortisol, are produced by a small gland (the adrenal gland) on top of each kidney. *Estrogens* are female hormones produced by the ovaries. *Androgens*, such as testosterone, are produced by the testicles.

Testosterone can promote growth of prostate cancer. That is why men with prostate cancer may take anti-androgen drugs to slow the cancer growth. Estrogens are rarely used to treat prostate cancer.

Some breast cancers depend on estrogen to grow. Drugs that block estrogen or reduce its production (such as tamoxifen or aromatase inhibitors) are used to slow the growth of these breast cancers or keep them from coming back.

Corticosteroids are used to treat many different kinds of cancer. They also help reduce nausea, improve appetite, and reduce swelling caused by cancer in the brain.

## What to look for

- Corticosteroids can cause short-term side effects such as:
  - 25) Mood changes
  - 26) Trouble sleeping
  - 27) Fluid retention
  - 28) More facial hair
  - 29) Increased urination
  - 30) Increased thirst and appetite
  - 31) Muscle weakness
  - 32) Fat build-up in the cheeks, abdomen, and the back of the neck
  - 33) Prolonged high doses can cause osteoporosis (bone thinning), which raises the risk of broken bones (fractures).
- Estrogens can cause short-term side effects. In women, estrogens can cause fluid retention and vaginal discharge or bleeding. In men, they can cause tender and swollen breasts and less interest in sex.
- Estrogen-blocking drugs such as tamoxifen can cause hot flashes and vaginal dryness and discharge in women.
- Androgen-blocking drugs may cause hot flashes in men, as well as less interest in sex, decreased sexual performance, tiredness, and mood changes.

## What the patient can do

- Talk with your doctor about what to expect from the hormones you will be taking.
- Cut back on your salt intake.
- Watch your calorie intake to avoid too much weight gain.
- Take your medicines as directed.
- Remember that these side effects are short lived and will get better after the steroid or hormone treatment is done.
- Do not suddenly stop taking your medicines. Talk with your doctor if there are problems.

## What caregivers can do

- Find out what medicines the patient is on. Talk with the doctor so that you will have some idea what to expect while the patient is on hormone therapy.
- Watch for mood swings.

### **Call the doctor if the patient:**

- Is vomiting or having pain in the abdomen
- Has mood swings that are disturbing you and others
- Is having trouble sleeping
- Becomes short of breath (See the section called "Shortness of breath.")
- Becomes dehydrated (See the section called "Fluids and dehydration.")
- Has a fever of 100.5° F or higher when taken by mouth
- Has stools that look black like tar or contain blood
- Has pain

For more in-depth information on the specific hormones you are taking, contact your American Cancer Society at 1-800-227-2345, or visit [www.cancer.org](http://www.cancer.org).

## **Stomas (or ostomies)**

A stoma is a surgically created opening in the body that replaces a normal opening. It is needed when the normal opening is blocked by a tumor or has been altered as part of cancer treatment. Stomas serve as new sites for basic bodily functions.

There are different types of stomas. Three are commonly seen in people with cancer:

- Tracheostomy (pronounced tray-key-OSS-tuh-mee, or trake for short) in the trachea, or windpipe
- Urostomy in the bladder or urinary system
- Colostomy in the colon

## What the patient can do

### **Tracheostomy:**

- Use pad and paper for "speaking" with others.

- Do not remove the outer tube of the tracheostomy unless your doctor or nurse tells you to.
- Clean your tracheostomy tube at least once a day as instructed by your nurse or doctor.
- Suction the tube as needed or as directed by your nurse or doctor.
- Wash your hands carefully before and after handling your tracheostomy to help prevent infections.
- Be careful to keep water out of the tracheostomy while bathing. A child's bib with the plastic side facing outward can be used to keep water out and allow breathing while you shower.
- Do not swim. Being around water that may get close to your neck will be risky for you because water can get into your lungs.
- Wear a scarf or shirt that covers the opening but is made of thin fabric (such as cotton) that allows air to get through. This helps protect the stoma from dust and loose fibers.
- Ask to meet with a respiratory therapist or ostomy nurse if you need more information.
- You may want to visit [www.theial.com](http://www.theial.com) or call 1-866-425-3678 to learn about the International Association of Laryngectomees.

### **Urostomy and colostomy:**

- Every day, gently clean the skin around your stoma with warm water only. (You may see a small amount of blood while cleaning. This is OK.)
- Gently pat dry or allow to air dry.
- Showers or baths can be taken with pouch on or off.
- Apply barriers, borders, or pastes to the skin around the stoma before putting on the pouch.
- Empty the pouch when it is one-third full.
- Change the colostomy pouch before there is a leak; if possible, not more than once a day and not less than once every 3 or 4 days.
- Change the urostomy pouch every 3 to 7 days.
- Irrigate the colostomy as instructed by a nurse or doctor.
- Ask your enterostomal therapy nurse any questions you may have.

- If you live in a large community, consider joining a support group. Visit [www.ostomy.org](http://www.ostomy.org) or call 1-800-826-0826 for information from United Ostomy Associations of America, Inc.
- See the section called "Sexuality" for tips on managing the stoma during sex.

## What caregivers can do

### **Tracheostomy:**

- Learn how to care for the tracheostomy.
- Learn to suction out mucus from the upper airway.
- Moist air helps keep mucus from being too thick and sticky. A humidifier, especially in the bedroom, may be helpful. Check with the doctor or nurse on how to clean the humidifier.

### **Urostomy and colostomy:**

- Learn how to care for the stoma, including the skin around it.
- Offer help if the patient is having trouble. Often, the patient feels embarrassed and will not ask for help.
- Encourage the patient to join an ostomy club for support and practical tips.

For more information on colostomy, ileostomy, or urostomy, contact your American Cancer Society at 1-800-227-2345, or visit [www.cancer.org](http://www.cancer.org).

## Swallowing problems

Swallowing problems occur when a person has trouble getting food or liquid down his throat. A person may gag, cough, spit, or feel pain when trying to swallow. There can be a number of causes. It may be a short-term side effect of chemo or radiation treatment to the throat or chest. It may also be caused by an infection of the mouth or esophagus (the swallowing tube that goes from the throat to the stomach), as well as other problems.

### What to look for

- Gagging, coughing, or vomiting of food
- Weight loss
- Food building up in mouth
- Drooling out of the side of mouth; too much saliva

- Little or no saliva
- Inside of mouth is red, shiny, glossy, or swollen
- Open sores in mouth
- Pain in throat or mid-chest when you swallow
- Feeling like the food is "sticking" on its way down
- White patches or a coating on the inside of the mouth

## What the patient can do

- Eat bland foods that are soft and smooth but high in calories and protein (such as pudding, gelatin, ice cream, yogurt, and milkshakes).
- Take small bites, and swallow each bite completely before taking another.
- Use a straw for liquids and soft foods.
- Try thicker liquids (such as fruit that has been pureed in the blender), because they are easier to swallow than thin liquids.
- Mash or puree foods (such as meats, cereals, and fresh fruits) so that they are as soft as baby food. You may need to add liquids to dry foods before blending.
- Dunk breads in milk to soften.
- Refrigerate food (the cold helps numb pain) or serve cool or lukewarm. (Pain in the esophagus may feel worse with cold liquids. If so, serve food at room temperature.)
- Try crushed ice and liquids at meals.
- Frequent small meals and snacks may be easier to manage.
- Crush medicines in pill or tablet form; mix in juice, applesauce, jelly, or pudding. (Check with your nurse or pharmacist first, because some medicines can be dangerous if crushed or broken. Others react badly with certain foods or must be taken on an empty stomach.)
- Avoid alcohol and hot, spicy foods or liquids.
- Avoid acidic foods, such as citrus fruits and drinks, or fizzy drinks (like cola or ginger ale).
- Avoid hard, dry foods such as crackers, nuts, and chips.
- Sit upright to eat and drink and for a few minutes after meals.

- If pain is a problem, use a numbing gel or pain reliever, such as viscous lidocaine (by doctor's prescription) or liquid Tylenol. (See the section called "Mouth sores.")
- Ask your doctor about seeing a speech therapist or swallowing therapist.

## What caregivers can do

- Offer soft, moist foods. Baked egg dishes, tuna salads, and thick liquids such as yogurt may be easier to swallow.
- Avoid chewy foods or raw, crunchy vegetables.
- Sauces and gravies make meats easier to swallow.

## Call the doctor if the patient:

- Gags, coughs, or chokes more than usual, especially while eating or drinking
- Has a severe sore throat
- Has a red, shiny mouth or ulcers in the mouth or on tongue
- Has a fever greater than 100.5° F when taken by mouth
- Has trouble breathing
- Has chest congestion
- Has problems with food "sticking" as it goes down
- Cannot swallow medicines or eat

## Sweating

Sweating is heavy perspiration that can happen at night or even when the room is cool. It can be heavy enough to soak a person's clothes. Such sweating is common when a fever breaks. You may notice sweating happens a short time after the person has shaking chills. (See the section called "Fever.")

You can have a fever with or without a known infection. Sometimes, no fever is detected, only the sweating that goes along with a drop or break in fever.

## What to look for

- Feeling wet or damp during the night or waking up to find sheets damp
- Fever followed by heavy sweating as the body temperature goes back down
- Shaking chills

- Drenching sweats even when there is no fever

## What the patient can do

- Take medicine to reduce fever, such as Tylenol, but only if instructed by the doctor or nurse.
- Dress in 2 layers of clothing. The layer on the outside will act as a wick to pull moisture up and away from the skin.
- Change wet clothes as quickly as possible.
- Keep your bed linens dry.
- Bathe at least once a day to soothe skin and to maintain good hygiene.

## What caregivers can do

- Help the patient keep clothes and bed linens dry.
- Check the patient's temperature several times a day to find out if there is fever. Wait 10-15 minutes after the patient eats or drinks to check temperature.
- Offer extra liquids to replace the fluid that is lost through sweat.
- For comfort, offer to help the patient with a tub bath or shower if needed.

## Call the doctor if the patient:

- Becomes dehydrated from frequent soaking sweats (See the section called "Fluids and dehydration.")
- Has fever of 100.5° F or higher (when taken by mouth) for more than 24 hours
- Has tremors or shaking chills

## Swelling

Swelling (edema) is a build-up of water in the tissues. Common causes include salt and water retention (due to medicines or heart, liver, or kidney failure), poor nutrition, pelvic tumors, or blockage in the veins or lymph system. Fluid can also build up in the abdomen. This is known as ascites (as-SIGH-tees). It makes the belly look swollen.

## What to look for

- Feet and lower legs get larger when you sit in a chair, stand, or walk

- Rings feel too tight for fingers
- Hands feel tight when making a fist
- Large, puffy, or blown-up abdomen (belly)
- Trouble breathing, especially when lying down (See the section called "Shortness of breath.")
- Heart racing or palpitations (or an awareness that the heart beat is fast or irregular)

## What the patient can do

- Limit your use of salt on food. Avoid use of table salt and salt in cooking, and don't eat foods that are very high in salt.
- Talk with the doctor about how to reduce your salt intake.
- Eat as well as you can. (See the section called "Appetite, poor.")
- Take medicines as prescribed by the doctor.
- Rest in bed with your feet up on 2 pillows.
- When sitting up in a chair, keep your feet level with your chest by placing them on a stool with pillows.

## What caregivers can do

- Watch for any new symptoms, especially shortness of breath or swelling in the face.
- Encourage the patient to keep the swollen body part propped up as high as is comfortable when sitting or lying down.
- Don't add salt, soy sauce, or monosodium glutamate during cooking.
- Weigh the patient every day or 2 on the same scale, at the same time of day. Keep a list of weights and dates.

## **Call the doctor if the patient:**

- Can't eat for a day or more
- Hasn't urinated, or has urinated very little, for a day or more
- Can press a finger into a swollen area and the fingertip mark remains
- Has swelling that spreads up legs or arms
- Develops a puffy or blown-up belly

- Feels that the swollen area is getting red or hot
- Has shortness of breath or a racing heart
- Has a swollen face and neck, especially in the mornings
- Gains 5 or more pounds in a week or less

## Treatment at home

Treatment for cancer sometimes can be given at home rather than in the hospital or clinic. Pills, intravenous (or IV) chemo, IV antibiotics, subcutaneous injections (shots given under the skin, also known as "sub-Q" injections), intramuscular injections (shots given into a muscle, also called "IM" injections), and other treatments may be given at home. Talk with your doctor about it. It is important to take medicines as prescribed and to look for side effects that sometimes happen. Usually, a home care nurse or IV therapy (infusion) nurse will come to your home often to give, teach you about, or check on home treatments.

Home treatments sometimes cannot be done due to problems with health insurance. You may want to contact your insurance company to find out more. Patients who cannot make frequent visits to the doctor's office or clinic may qualify for some kinds of home care. To be eligible for this, you must be homebound, only going out for doctor's visits or church.

## What the patient can do

### Pills:

- Take your pills *exactly* as you were told to.
- You may have to set an alarm for the middle of the night so you can take your pills at the right time. Put the pill dose and a glass of water on your bedside table so you don't have to get up.
- If taking pills only once a day, you may want to try taking them just before bedtime to avoid side effects, such as nausea. Check with your doctor or nurse about the best time and way to take each medicine.
- Ask your doctor or nurse about any side effects you may have and about ways to control these side effects. (For instance, if your pills could cause nausea, should you take them before meals? Is there something else you can take that would help?)
- Keep all medicines out of the reach of children and pets.
- Check with your doctor, nurse, or pharmacist before you cut or crush your pills. Some time-released drugs can be dangerous if the pills are broken.

## **Intravenous (IV) medicine:**

- A home health or infusion nurse will come to your home to give drugs intravenously (into a vein) or to teach you and your family how to do so.
- See the section called "Tubes and IV lines" for further information on care of the IV site.

## **Injections (under the skin or into a muscle):**

- Wash your hands well with soap and water before starting.
- Take medicines as instructed by your doctor or nurse.
- Check to be sure that the dosage in the syringe is your prescribed dosage.
- Wipe your skin with alcohol and let it dry for 30 seconds before injecting.
- If the needle touches anything that isn't sterile before you use it to inject, throw the needle away, put a new one on the syringe, and start over.
- Use a different place on the body for each shot.
- For shots under the skin, use a site at least 1 inch away from the place you used before.
- For intramuscular injections (shots into a muscle), ask for a picture or chart of places on the body that are safe to use.
- Check old injection sites for signs of infection, including redness, warmth, swelling, pain, or oozing. A temperature over 100.5° F or higher when taken by mouth may be a sign of infection.
- Throw away used needles and syringes in an empty coffee can with a lid or an empty plastic bleach bottle. Take the full container to the clinic for proper disposal. Or ask the home health nurse if you can get a needle disposal box. Keep the needle container away from children, pets, and visitors.

## **What caregivers can do**

- Learn how to give the medicines in case the patient can't do it.
- If you help with shots, be careful to not stick yourself with the needles. Put the used needle container near the patient before you start. Drop the needle and syringe in as soon as you're finished. Don't put the cap back on the needle before throwing it away.
- Keep the doctor's office number (including emergency numbers) handy.

- If you have a home health nurse who helps with injections, keep his phone number nearby in case you have questions.

### **Call the doctor if the patient:**

- Is about to need a prescription refill
- Spills or loses medicine, or if a dose is vomited or thrown up
- Learns that any person, other than himself, has taken his medicine
- Misses a dose
- Has redness, warmth, swelling, drainage, or pain at any injection site
- Has a fever greater than 100.5° F when taken by mouth
- Has uncomfortable side effects, such as nausea, vomiting, diarrhea, or pain
- Cannot give himself the shots or take the pills for any reason
- Notices itching, dizziness, shortness of breath, hives (raised itchy skin welts), or other signs of an allergic reaction after a shot (If this is the case, call emergency medical services (911) before calling the doctor.)

## **Tubes and IV lines**

Tubes and intravenous, or IV, lines allow liquid medicines, fluids, and even nourishment to flow into the body. See the section called "Treatment at home" for more information on tubes and IV lines.

**Intravenous (IV)** lines are thin, flexible, plastic hoses that run from a bottle or bag of medicine into a tiny needle or intravenous catheter (a small, flexible tube) placed in a vein in your body. Some patients may have a port (like a small drum) permanently placed in the chest or arm. Special needles are then put into the port. Some patients may have long-term tubes (catheters) that require no needles.

Some medicines are injected into the catheter. Other medicines and fluids are given slowly (infused). The speed (rate) of the infusion is set by a roller clamp on the tube, by a balloon that squeezes out the medicine, or by an electronic pump.

**Tube feedings** are liquid food that is given through a tube placed in the stomach or the small intestine. The tube may go in through the nose or the wall of the stomach.

**Oxygen** may be given through masks or little tubes placed just inside the nostrils called nasal cannula. Tubing connects the mask or cannula to the oxygen tank or oxygen concentrator.

An important difference between these types of tubes is that anything that goes in the IV line must be sterile (completely germ free) in order to avoid putting germs into the

bloodstream and causing infections. IV equipment is used only once. It must be handled carefully to keep germs out of the body. After use, it is thrown out and replaced with new, sterile equipment fresh out of the package.

Tube feedings and oxygen tubes are kept clean, but do not have to be sterile. Tube feeding or oxygen equipment can be re-used as long as it is used by the same person. When tube feeding bags need cleaning, liquid soap and water are fine.

People getting chemo, antibiotics, hyperalimentation (hi-per-al-uh-men-TAY-shun, also called total parenteral nutrition, or TPN), tube feedings, and/or oxygen at home may be faced with many tubes and IV lines that they must learn to keep track of and use safely. At first it may seem confusing, but you can master taking care of many tubes or lines. A home health nurse will help you learn. Usually, chemo and blood products are given by a nurse who comes to your home. You and your family will be able to manage most other IV medicines. If you cannot, other plans will be made for you to get your treatment.

## What the patient can do

### IVs:

- Focus on only 1 set of lines at a time. If you get frustrated, just take a deep breath and start again.
- Color code each set of lines with colored tape. For example, red for chemo, green for antibiotics, etc. Keep a record of what you have marked. You may want to use blue tape on oxygen tubes to keep them clearly separate from the IV lines.
- For permanent IV sites (such as Hickman<sup>®</sup>, Port-a-Cath<sup>®</sup>, PasPort<sup>®</sup>, or Infusaport<sup>®</sup>):
  - Keep extra clamps handy at all times.
  - If a tube breaks and you notice blood leaking out, clamp the tube between your body and the leak and call your doctor right away.
  - Shower facing away from the showerhead. If you have an electric pump, unplug it before showering or bathing to avoid an electrical hazard. Try to keep the dressing dry, but change it if it gets wet.
  - Watch for redness, swelling, pain, and tenderness at the site.
  - Use a calendar to record when you change injection caps and dressings and to note delivery dates, daily weights, and urine testing results. It is also helpful to record your daily fluid intake and output (how much liquid you drink and infuse, and how much urine you put out.) Your doctor or nurse will tell you what things you need to keep track of.
- Keep the IV site clean and dry.

- Avoid the temptation to speed up your IV medicines or fluids. Many IV medicines and fluids can harm you if they go in too fast.
- Wash your hands well with soap and water before touching the IV site.
- Check the IV site daily:
  - Look for any tenderness, pain, redness, burning, swelling, or warmth; any slowing of the flow rate of the IV; or drainage (bloody, yellowish, or clear). Any of these might mean the site is getting infected or clogged.
  - Be sure the tape is holding the IV in place and the dressing is clean and dry.
  - Take your temperature each day to see if you have a fever. (See the section called "Fever.")
  - If you notice any of the above symptoms, take off the dressing, look at the IV site and tell your doctor or home health nurse what you found.
- If the IV comes out or the site begins to bleed, call your doctor or nurse right away.
- Avoid activities that may pull out the IV or rub on the dressing.
- Keep a daily log of procedures performed.

### **Hyperalimentation (TPN or total parenteral nutrition):**

- Your home care nurse will teach you exactly how to begin and end each infusion.
- Infuse TPN slowly overnight so that you have more free time during the day.
- If you find that you are having trouble sleeping because you need to go to the bathroom often, TPN may be infused during the day or early evening. It must still go in slowly.
- Intravenous fat emulsions are usually given along with TPN 2 to 7 times a week. They provide essential fatty acids and increase calorie intake. Fat emulsions can be added to the TPN solution through a port on the TPN tubing. These can be infused by gravity (without a pump) in adults. Your home health nurse will show you how to set the speed by using the roller clamp and timing it to give you the right number of drops per minute. A pump is needed for children.
- Infuse your TPN in a room near a bathroom so that you do not have to carry the pump too far. Use a night light so that if you need to get up at night, you don't trip over or pull the tubing.
- Most pumps are battery powered. Check with the home health nurse about how long the pump can run before new batteries are needed. Be sure that you have enough batteries for your type of pump, and know how to put them in.

- Keep a clean work area for supplies.
- If possible, use a separate place in the refrigerator (or a separate refrigerator if you have an extra one) for IV solutions.
- Throw away needles and syringes in a metal coffee can with a lid, in a bleach bottle, or in a used needle container provided by the home health team. Keep the container out of the reach of children, pets, and others.
- Always check the expiration date on all your supplies.
- Home health care nurses will draw blood samples to check blood counts.

### **Tube feedings:**

- The tubes used for tube feedings may be short or long term. The nasogastric (NG) tube, which runs from nose to stomach, is short term. Jejunostomy tubes (J-tubes) or gastrostomy tubes (G-tubes), which are surgically placed in the upper intestine or stomach and come out through the belly, are for long-term use.
- Tube feedings are best given at night.
- Feedings usually consist of products like Ensure or Sustacal.
- Give tube feedings at room temperature. Most do not need to be refrigerated.
- Check the placement of NG tubes as instructed by your doctor or nurse.
- Pour the feeding liquid into the special feeding bag.
- Allow the liquid to run through the entire tubing. Tap the tube to make air bubbles rise. (It takes about 3 to 4 feet of air in the tube before it causes problems.)
- Attach the tube containing the liquid food to NG, G-tube, or J-tube. Tape the connection.
- Set the pump to the required rate.
- Add more feeding liquid to bag as needed.
- Rinse tubes and bag with water after the infusion is completed.
- Cap off the tube as instructed.
- Feedings can also be given with large syringes instead of bags and tubing. Be sure you are comfortable using whichever method you are taught.
- Check the skin around the tubes each day for redness, drainage, or skin problems.
- Apply petroleum jelly (such as Vaseline<sup>®</sup>) to the nostrils if an NG tube is in place.

- Change the tape at the NG tube every other day. Be sure the skin around the nose and nostril is not sore, red, or painful.
- Always keep the feeding tubes securely taped in place. If the tube seems to be coming out, tape it in place, and do not use it. Call your doctor or home health nurse to find out what needs to be done.
- Weigh yourself each day and write down dates and weights.

### **Oxygen:**

- Be sure you know how to turn the oxygen on and off and set the flow rate. Never increase the oxygen flow above the prescribed level.
- The nurse will show you how to use the oxygen mask or nasal cannula.
- Use a water-based lubricant, rather than petroleum jelly, on the lips and cheeks.
- If the nasal cannula rubs your upper lip, you can put a small piece of gauze or fabric under it for padding.
- Keep a new tank of oxygen available at all times. Even if you use an oxygen machine, you will need a small tank for when you leave the house and during power failures.
- If you use a tank, be sure it is attached to a stable cart so it won't fall or roll.
- Do not smoke or go near sparks or flames while using oxygen. Keep sparks and flames away from tanks, oxygen machines, and tubing.

### **What caregivers can do**

- Learn as much as you can about how to use the tubes and equipment, and practice while the home health nurse is there to watch you. You may need to do these tasks when the patient cannot.
- Help the patient. At first, you will probably both feel more comfortable if you do these treatments together.
- Keep home health nurses' phone numbers handy, and call when you have questions or problems.
- Be sure that the patient keeps all appointments.
- Watch for confusion, especially at night.

### **Call the doctor if the patient:**

- Has redness, swelling, drainage, pain, tenderness, or warmth at an IV site or at the site of a permanent IV access device

- Has a temperature of 100.5° F or higher when taken by mouth
- Has bleeding from the IV or access site
- Cannot flush or use his catheter or tube
- Becomes confused, disoriented, or unusually drowsy
- Becomes more short of breath
- Develops a cough
- Has diarrhea for more than 1 day

## Weakness

A person who has trouble moving may have general weakness and problems walking, and he may find it hard to get from one place to another. When a person spends a lot of time in bed, muscles get weaker. Other things that can make it hard to move include pain in the joints or legs, as well as some of the side effects of chemotherapy and radiation. It is important to move and exercise as much as possible to prevent new problems. Problems caused by being less active may include poor or no appetite, constipation, skin sores, problems with breathing, stiff joints, and mental changes.

## What the patient can do

- Do active or passive range-of-motion exercises as instructed by the nurse, doctor, or physical therapist. (See the section called "Exercise.")
- Take pain medicines as prescribed.
- Drink as much liquid as your doctor will allow.
- Keep a record of bowel movements. (See the section called "Constipation" for information about foods that help prevent this problem.)
- Change positions at least every 2 hours while at rest.
- Wear shoes (not slippers that slide off easily) when walking or standing.
- Use any brace, cane, walker, or other support prescribed by your doctor or nurse.
- Take short walks if you can. Even if you are bedridden, try to sit up in a chair for meals and walk to the bathroom or bedside commode.
- If you need help walking, have a family member support you on your weakest side. (For instance, if your right side is weak, have someone stand on your right side before you get up. Have your helper put his left arm around you, and put his right forearm and hand in front of your right shoulder.)

## What caregivers can do

- When lifting the patient, keep your back straight and bend and lift from your knees and hips. Stand as close to the patient as possible, and keep your feet spread for a firm base and good balance.
- Always lock the wheels on the bed or wheelchair.
- Always pull the patient toward you when rolling him in bed.
- Clear the floor so that you can help the person to the chair or bathroom without tripping over rugs, cords, fallen objects, or clothing, and without slipping on liquids.
- If the patient is unsteady but still able to get up, see the section called "Falls."
- If the patient is to be alone for a while, be sure that the phone and emergency phone numbers are within easy reach.

### **Call the doctor if the patient:**

- Is getting weaker
- Falls
- Has a headache, blurred vision, numbness, or tingling
- Has a change in mental status, such as getting confused, disoriented, or very sleepy
- Has pain that gets worse

## Weight changes

Weight changes during treatment for cancer are common. There are a number of causes for weight loss including:

- Eating less due to nausea or poor appetite
- Diarrhea
- Vomiting
- Dehydration

(You can learn more about each of these in their related sections.)

Causes for gaining weight include:

- Less activity
- Eating more

- Retaining water (See the section called "Swelling.")
- Certain medicines

Weight changes of more than 5 pounds in a week should be reported to your doctor. A decrease in weight over time may affect the patient's ability to function, and make them weak and unable to perform daily activities. Quick weight loss is often a sign of dehydration. An increase in weight over time may suggest a serious health condition, such as diabetes or high blood pressure. You may be able to tell if you gain or lose 5 pounds in a week by the way you feel or the way your clothes fit, or you can weigh yourself on a scale once a week or so.

## What to look for

- Weight loss of 5 pounds or more in a week or less
- Dry skin
- Fatigue, weakness
- Feeling very thirsty
- Dizziness
- Clothes or rings are too big

**OR**

- Weight gain of 5 pounds or more in a week or less
- Swollen ankles
- Shortness of breath
- Feeling puffy or bloated
- Tight shoes, clothes, or rings

## What the patient can do

### If you have lost weight:

- Drink extra high-protein and high-calorie fluids between meals.
- Be sure to drink enough water or other liquids that have no caffeine.
- Eat high-protein foods. You may also try liquid food supplements.
- Ask your doctor or nurse to arrange a meeting with a dietitian.

### If you have gained weight:

- Talk with your doctor or nurse about limiting fluid if your ankles are swollen.

- Limit your salt intake.
- Limit high-calorie foods.
- Ask your doctor or nurse to arrange a meeting with a dietitian.

## What caregivers can do

- Weigh the patient at the same time every day and write it down along with the date. In the morning, before breakfast, is a good time.
- Talk to the doctor if the patient's weight loss or weight gain concerns you.
- Watch the patient for other symptoms.

## Call the doctor if the patient:

- Loses or gains more than 5 pounds in a week
- Has shortness of breath
- Feels dizzy or becomes confused

## When death is approaching

When you are caring for a loved one who has advanced cancer, you may be there at the time of death. The following covers common events that often happen near the end of life. Knowing more about what to expect may help ease some of the anxiety around events that might otherwise be alarming. This section lists some signs that death may be close.

People often use this time to gather the family to say goodbye to their loved one. They may take turns with the patient, holding hands, talking to the patient, or just sitting quietly. It can also be a time to perform any religious rituals and other activities the patient wants before death. It is a chance for many families and friends to express their love and appreciation for the patient and for each other.

It is important to have a plan for what to do after death, so that people will know what to do during this very emotional time. If the patient is in hospice, the hospice nurse and social worker will help you. If the patient is not in hospice, talk with your doctor about it so that you will know what to do at the time of death. Not all of the following symptoms will happen, but it may be comforting to know about them.

For more information on hospice or what to expect when death is approaching, contact the American Cancer Society at 1-800-227-2345 and ask for our documents called *Hospice Care* and *Nearing the End of Life*. You can also find more information on our Web site, [www.cancer.org](http://www.cancer.org).

## What to look for

- Profound weakness – usually the patient cannot get out of bed and has trouble moving around in bed
- Patient needing help with nearly everything he does
- Less and less interest in food, often with very little food and fluid intake for days
- More drowsiness – the patient may doze or sleep much of the time if the pain is relieved or may be hard to rouse or wake
- A short attention span from the patient, who may not be able to focus on what is happening
- Confusion about time, place, or people
- Trouble swallowing pills and medicines
- Limited ability to cooperate with caregiver

## Possible changes in body function

- Weakness – has trouble moving around in bed and most likely is not able to get out of bed
- Cannot change positions without help
- Trouble swallowing food, medicines, or even liquids
- Sudden movement of any muscle, jerking of hands, arms, legs, or face

## What caregivers can do

- Help patient turn and change positions every hour or 2.
- Avoid sudden noises or movements to lessen the startle reflex.
- Speak in a calm, quiet voice to reduce your chances of startling the patient.
- If the patient has trouble swallowing pain medicines, ask the doctor or hospice nurse about getting liquid pain medicines or a pain patch.
- If the patient is having trouble swallowing, avoid solid foods. Give ice chips or sips of liquid through a straw.
- Do not push the patient to drink fluids. Near the end of life, some dehydration is normal and is more comfortable for the patient.
- Apply cool, moist cloths to the patient's head, face, and body for comfort.

## Possible changes in consciousness

- More sleeping during the day
- Hard to wake or rouse from sleep
- Confusion about time, place, or people
- Restless – may pick or pull at bed linens
- May talk about things unrelated to the events or people present
- May be more anxious, restless, fearful, and lonely at night
- After a period of sleepiness and confusion, may have a short time when he is mentally clear before going back into semi-consciousness

### **What caregivers can do**

- Plan your times with the patient when he is most alert or during the night when your presence may be comforting.
- When talking with the patient, remind him who you are and what day and time it is.
- Continue pain medicines up to the end of life.
- If the patient is very restless, try to find out if he is having pain. If it appears so, give breakthrough pain medicines as prescribed, or check with the doctor or hospice nurse if needed. (See the section called "Pain.")
- When talking with a confused person, use calm, confident, gentle tones to reduce the chances of startling or frightening the patient.
- Touching, caressing, holding, and rocking are usually helpful and comforting.

## Possible changes in metabolism

- The patient may have less interest in food. (The patient has less need for food and drink.)
- Mouth may dry out. (See "Possible changes in secretions" below.)
- The patient may no longer need some of his medicines, such as vitamins, chemo, replacement hormones, blood pressure medicines, and diuretics, unless they help make the patient more comfortable.

### **What caregivers can do**

- Apply lubricant or petroleum jelly (such as Vaseline) to the lips to prevent drying.

- Offer ice chips from a spoon, or sips of water or juice from a straw. These may be enough for the patient.
- Check with the doctor to see which medicines may be stopped. Medicines for pain, nausea, fever, seizures, or anxiety should be continued to keep the patient comfortable.

## Possible changes in secretions

- Mucus in the mouth may collect in the back of the throat. (This can be a very distressing sound to hear, but it usually isn't uncomfortable to the patient.)
- Secretions may thicken due to a lower fluid intake and build up because the patient cannot cough.

## What caregivers can do

- If mouth secretions increase, keep them loose by adding humidity to the room with a cool mist humidifier.
- If the patient can swallow, ice chips or sips of liquid through a straw may thin the secretions.
- Change the patient's position. Turning the patient to the side may help secretions drain from the mouth. Continue to clean the patient's teeth with a soft toothbrush or soft foam mouth swabs.
- Certain medicines may help – ask your hospice or home care nurse.

## Possible changes in circulation and temperature

- Arms and legs may feel cool to the touch as circulation slows down.
- Skin of arms, legs, hands, and feet may darken in color and look blue or mottled (blotchy).
- Other areas of the body may become either darker or paler.
- Skin may feel cold and either dry or damp.
- Heart rate may become fast, faint, or irregular.
- Blood pressure may get lower and hard to hear.

## What caregivers can do

- Keep patient warm with blankets or light bed coverings.
- Avoid use of electric blankets, heating pads, etc.

## Possible changes in senses and perception

- Vision may become blurry or dim.
- Hearing may decrease, but most patients are able to hear you even after they can no longer speak.

### **What caregivers can do**

- Leave indirect lights on as vision decreases.
- Never assume the patient cannot hear you.
- Continue to speak with and touch the patient to reassure him of your presence. Your words of affection and support are likely to be understood and appreciated.

## Possible changes in breathing

- Breathing may speed up and slow down due to less blood circulation and build-up of waste products in the body.
- Mucus in the back of the throat may cause rattling or gurgling with each breath.
- The patient may not breathe for periods of 10 to 30 seconds.

### **What caregivers can do**

- Put the patient on his back, or slightly to one side.
- Raise the patient's head, which may give some relief.
- Use pillows to prop up the patient's head and chest at an angle, or raise the head of a hospital bed.
- Any position that seems to make breathing easier is OK, including sitting up with good support. A small person may be more comfortable in your arms.

## Possible changes in elimination

- Smaller amounts of urine, which may be darker in color
- When death is near, loss of control of urine and stool

### **What caregivers can do**

- Pad the bed beneath the patient with layers of disposable waterproof pads.
- If patient has a catheter, the home health nurse will teach you to care for it.

## Signs that death has occurred

- Breathing stops
- Blood pressure cannot be heard
- Pulse stops
- Eyes stop moving and may stay open
- Pupils of the eyes stay large, even in bright light
- Control of bowels or bladder is lost as the muscles relax

## What caregivers can do

- After death occurs, it is OK to sit with your loved one for a while. There is no rush to get anything done right away. Many families find this is an important time to pray or talk together and reconfirm your love for each other as well as for the person who has passed away.
- If the patient dies in the home, caregivers are responsible for calling the proper people. Regulations or laws about who must be notified and how the body should be moved differ from one community to another. Your doctor or nurse can get this information for you. If you have a hospice or home care agency involved, call them. If you have completed funeral arrangements, calling the funeral director and doctor are usually all you have to do.

**An important note:** If you call 911 or emergency medical services (EMS), even after an expected death at home, the law often requires that EMS try to revive the patient or take him to a hospital. This can complicate the situation and delay funeral plans. Be sure that family and friends are ready and know exactly whom to call, so that they don't dial 911 in confusion or panic.

## To learn more

### More information from your American Cancer Society

The following information may also be helpful to you. These free materials may be ordered from our toll-free number, 1-800-227-2345, or read on our Web site, [www.cancer.org](http://www.cancer.org).

A Message of Hope: Coping With Cancer in Everyday Life (also available in Spanish)

Advance Directives

Advanced Cancer

American Cancer Society Cancer Survivors' Network (CSN)

Anemia in People With Cancer

Anxiety, Fear, and Depression

Bone Marrow and Peripheral Blood Stem Cell Transplant

Bone Metastasis

Coping With the Loss of a Loved One (also available in Spanish)

Family and Medical Leave Act

Fatigue in People With Cancer

Fertility and Cancer: What Are My Options?

Financial Guidance for Cancer Survivors and Their Families: Advanced Illness

Health Insurance and Financial Assistance for the Cancer Patient (also available in Spanish)

Helping Children When a Family Member Has Cancer: Dealing With a Parent's Terminal Illness

Helping Children When a Family Member Has Cancer: Understanding Psychosocial Support Services

Home Care Agencies (also available in Spanish)

Hospice Care (also available in Spanish)

Listen With Your Heart (also available in Spanish)

Nausea and Vomiting

Nearing the End of Life (also available in Spanish)

Nutrition for the Person With Cancer: A Guide for Patients and Families (also available in Spanish)

Oral Chemotherapy: What You Need to Know

Pain Control: A Guide for Those With Cancer and Their Loved Ones (also available in Spanish)

Sexuality for the Man With Cancer (also available in Spanish)

Sexuality for the Woman With Cancer (also available in Spanish)

Talking With Friends and Relatives About Your Cancer (also available in Spanish)

Talking With Your Doctor (also available in Spanish)

Understanding Chemotherapy: A Guide for Patients and Families (also available in Spanish)

Understanding Radiation Therapy: A Guide for Patients and Families (also available in Spanish)

Understanding Your Lab Test Results

## **Books**

The following books are available from the American Cancer Society. Call us at 1-800-227-2345 to ask about costs or to place your order.

*Cancer in the Family: Helping Children Cope With a Parent's Illness*

*Couples Confronting Cancer*

*What Helped Me Get Through: Cancer Patients Share Wisdom and Hope*

*When the Focus Is On Care: Palliative Care and Cancer*

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1 · 800 · ACS-2345 or [www.cancer.org](http://www.cancer.org)