



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

This guide gives you general information about caring for someone with cancer at home. It's an ABC list of the common problems people with cancer have. It gives you signs of problems to watch for and ideas for what you can do if problems come up. It also tells you when you should call your cancer team. One of the most important things to know about caring for someone with cancer at home is how to reach a member of your cancer team at any time, including after hours, weekends, and holidays. Be sure you have a phone number to call if problems come up.

The information given here is not meant to take the place of talking with a health professional. The people who know your situation well can give you the information that you need the most.

We have a lot more information on cancer, cancer treatment, and side effects that may be helpful to you. You can get it from your local American Cancer Society office, on our website at [www.cancer.org](http://www.cancer.org), or by calling us anytime, day or night, at 1-800-227-2345.

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

## Anemia

Anemia is a condition caused by a low hemoglobin level in the blood. It's common during cancer treatment.

On a blood test, the hemoglobin percentage measures the ability of the red blood cells to carry oxygen.

- For men: A normal hemoglobin range is about 14.5 to 18.
- For women: A normal hemoglobin range is about 12 to 16.

Most people still feel well with a hemoglobin percentage as low as 10. Feeling tired is a common sign of anemia.

## What to look for

- New or worsening tiredness that makes it harder to do your regular activities
- Chest pain or shortness of breath when you're active
- Pale skin, nail beds, or gums
- Dizziness
- Weakness
- Bright red, dark red, or black stool (poop)
- Dark brown or bright red vomit

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

## What the patient can do

- Balance rest and activities.
- Tell your cancer team 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 (such as fish, meat, eggs, cheese, milk, nuts, peas, and beans).
- Drink 8 to 10 glasses of water a day, unless you are given other instructions. It's OK to drink other liquids instead of water – just not beer, wine, or other alcoholic drinks.

## What caregivers can do

- Schedule friends and family members to prepare meals, clean the house, do yard work, or run errands for the patient. You can use websites that help organize these things, or get someone else to look into this for you.
- Watch for confusion, faintness, or dizziness.

## **Call the cancer team if the patient:**

- Has chest pains
- Has shortness of breath when resting

- Feels dizzy or faint
- Gets confused or can't concentrate
- Has not been able to get out of bed for more than 24 hours
- Has blood in their stool
- Has dark brown or bright red vomit

## **Anxiety, fear, and emotional distress**

Anxiety (a feeling of worry or unease), fear, uncertainty, anger, and sadness are common feelings that patients and families sometimes have when coping with cancer. They are normal responses to the many stresses of cancer.

You may have trouble with your family duties and the loss of control over events in your life. Changes in the way you look, or simply the shock of finding out you have cancer might lead to feelings of fear or anxiety. Many people feel uncertain about the future and worry about suffering, pain, and the unknown. It's normal to mourn changes in your body, and maybe losing the healthy future you wanted. Fears about loss of independence, changes in relationships, and being a burden to others can be too much to deal with all at once.

Family members may have these feelings because they, too, are uncertain about the future or maybe even angry that their loved one has cancer. They may feel guilty and frustrated at not being able to "do enough" as they care for the patient and family. Or it might seem like it's too much to do everything they now have to do. Many caregivers feel stressed trying to balance work, child care, self-care, and other tasks, along with this extra work. 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 day-to-day life. If this happens, it often helps the patient and family to get help from a mental health therapist or counselor.

### **What to look for**

- Feeling anxious, swamped, or overwhelmed
- Trouble thinking, solving problems, or making decisions (even about little things)
- Feeling agitated, irritable, restless, or panicked
- Feeling or looking tense
- Concern about "losing control"

- An uneasy sense that something bad is going to happen
- Trembling or shaking
- Headaches
- Being cranky or angry with others
- Trouble coping with tiredness, pain, nausea, and other symptoms
- Problems 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 or others when you feel anxious and afraid. Instead, look at your thoughts, concerns, and beliefs about what has been going on in your life.
- Get help through in-person or online support groups.
- Think about asking your cancer team to refer you to a counselor or mental health professional who can work with you and your family.
- 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 part of your body, 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 (coffee, tea, energy drinks). It can make anxiety worse.
- Talk with your cancer team about medicines for anxiety.

## What caregivers can do

- Gently invite the patient to talk about their fears and concerns.
- Don't try to force the patient to talk before they are ready.
- Listen carefully without judging the patient's feelings – or your own.
- Talk with the patient to decide what you can do to better support each other.

- For severe anxiety, it's usually not helpful to try to reason with the patient. Instead, talk with the cancer team about the symptoms and problems you notice.
- To reduce your own stress, try suggestions from the list for the patient, or use other stress relievers that have worked for you in the past.
- Consider getting support for yourself through groups or one-on-one counseling.

### **Call the cancer team if the patient**

- Has trouble breathing
- Is sweating or flushed, 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 starting a new medicine, talk with the cancer team about it.

See the section called “Depression” for more on this.

## **Appetite, poor**

A person with a poor appetite or no appetite may eat much less than normal or may not eat at all. A poor appetite can be caused by a changed sense of taste or smell, feeling full, tumor growth, dehydration (see the section called “Fluids (lack of) and dehydration”), or the side effects of treatment. A poor appetite can be made worse by many things, such as trouble swallowing, depression, pain, nausea, or vomiting. (More information on these causes is given in the related sections.) A poor appetite is most often a short-term problem.

### **What to look for**

- Little or no interest in food
- Refusing to eat favorite foods
- Weight loss

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

- Talk with your cancer team 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.
- Try foods high in calories that are easy to eat (such as pudding, ice cream, sherbet, yogurt, milkshakes, or cream-based soups).
- 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. (Drinking liquids at mealtime can fill you up.)
- Try light exercise an hour before meals.
- Hard candies, mint tea, or ginger ale might help get rid of strange tastes in your 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. (Your cancer team can make suggestions and may have samples you can try.) Use a straw if it helps.

## 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, serve bland foods 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 if the patient refuses food or can't eat.
- Be encouraging, but try not to nag or fight about eating.
- If the patient can't eat, you might want to offer just your company. Or offer to read to them or give them a massage.

### **Call the cancer team if the patient:**

- Feels nauseated and can't eat for a day or more
- Loses 5 pounds or more
- Has pain when eating
- Doesn't urinate (pee) for an entire day or doesn't move bowels (poop) for 2 days or more
- Doesn't urinate often, and when they do, it 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's not controlled

## **Bleeding or low platelet count**

Cancer and cancer treatments can lower the number of platelets in your blood. Platelets are cells that help your blood clot, so you stop bleeding.

A normal platelet (PLT) count on a blood test is about 150,000 to 450,000. Normal clotting is still possible with a platelet count of 100,000. The danger of serious bleeding is very high when the platelet count goes below 20,000.

### **What to look for**

- Bleeding from anywhere (such as the mouth, nose, or rectum)
- Bloody or dark brown vomit that looks like coffee grounds
- Bright red, dark red, or black stools (poop) (See the sections called "Blood in stool" and "Blood in urine" for more on this.)
- Women may have heavy vaginal bleeding during monthly periods

- New bruises on the skin
- Red pinpoint dots on the skin, usually starting on feet and legs
- Bad headaches, dizziness, or blurred vision
- Weakness that gets worse
- Pain in joints or muscles

## 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 lead to injury.
- Protect your skin from cuts, scrapes, and sharp objects.
- Use a soft toothbrush.
- If your mouth is bleeding, rinse it a few times with ice water.
- Talk to your cancer team about whether you should put off flossing your teeth until your platelet counts improve.
- Do not blow your nose or cough with great force.
- Keep your head level with or above your heart (lie flat or stay upright).
- Use a stool softener to avoid constipation and straining during a bowel movement. Do not use enemas or suppositories of any kind. (If you're constipated, see the section called "Constipation.") Check with your cancer team before using laxatives.
- Do not put anything in your rectum, including suppositories, enemas, thermometers, etc.
- Stay away from anti-inflammatory pain medicines, such as aspirin, naproxen, or ibuprofen (Motrin<sup>®</sup>, Advil<sup>®</sup>, Naprosyn<sup>®</sup>, Aleve<sup>®</sup>, Midol<sup>®</sup>) and medicines like them unless your cancer team tells you to use them. Check with your pharmacist if you're not sure whether a medicine is in this class of drugs, or if it contains one of 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 or paper towel until bleeding stops.

### **Call the cancer team if the patient:**

- Is bleeding or has any of the symptoms listed in the “What to look for” section
- Has trouble speaking or moving

## **Blood counts, changes in**

Cancer and cancer treatment often cause drops in blood count levels. The problems caused by low blood counts depend on which type of blood cell is affected.

For more on low red blood cell (hemoglobin or HGB) counts, see the section called “Anemia.”

For more on low white blood cell (WBC) counts, see the section called “Infection, increased risk.”

For more on low platelet (PLT) counts see the section called “Bleeding or low platelet count.”

After cancer treatment, it may take a few weeks for your counts to get back to normal. Call us at 1-800-227-2345 or visit [www.cancer.org](http://www.cancer.org) if you would like to know more about what your blood test results mean.

## **Blood in stool**

Blood in the stool (poop) may be caused by irritation when moving the bowels. 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), or by a low platelet count. (See the section called “Bleeding or low platelet count.”)

### **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 2 to 3 days. This is normal.)

## What the patient can do

- Check how much blood is being passed.
- Don't put anything in your rectum, including suppositories, enemas, thermometers, etc.
- Keep stool soft by taking in plenty of fluids and fiber.
- Use stool softeners if OK with your cancer team.
- 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 cancer team if the patient:**

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

## Blood in urine

Blood can be seen in the urine (pee) when a patient is bleeding in some part of their kidneys or bladder, or in the tubes that carry urine. The blood is being flushed out along with the urine. Bleeding can be caused by infection, injury, tumors, or stones that are in the kidneys, tubes, or bladder. It can also be due to a low platelet count. (For more information on low platelet counts, see the section called "Bleeding or low platelet count.")

## 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 you've been told to limit the amount you drink.
- Take medicines as prescribed.

## What caregivers can do

- Offer extra fluids.
- Help the patient check the color of their urine, if needed.

## **Call the cancer team if the patient:**

- Sees bloody urine (red, pink, or brown)
- Has pain in lower back or on lower sides of the back
- Has 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
- Can't urinate
- Has a fever of 100.5° F or higher 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 they normally do, they may be confused. Many things can cause confusion, including:

- Low blood sugar
- Infection
- High fever

- Cancer spread into the brain
- Cancer in the fluid around the brain
- Lack of oxygen to the brain
- Anemia (See the section called “Anemia.”)
- Too much calcium in the blood
- Intense pain
- Too much pain medicine
- Other medicines

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 cancer team right away. The patient may need to be seen 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’s 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 they were able to manage alone before
- Cloudy, disorganized thinking or the patient not knowing where they are
- Sudden changes in emotion; for instance, quick shifts from happy to irritated
- Forgetting what they are doing

## What the patient can do

- Call your cancer team 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 appointments with the patient so that you can describe the patient’s problems and remember instructions for them.

- Focus attention by gently touching the patient and facing the patient when talking to them.
- Stay within a few feet of the patient when you're talking to them.
- 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 and time, and where they are.
- 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 they are.
- 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 hand washing, going to the bathroom, bathing, and other daily activities that may be hard for them to do alone.
- Check to see what the patient eats. (They may forget to eat, or may not be able to eat.)
- Be sure that the patient takes the right medicines the right way.
- Keep medicines out of reach between doses.

### **Call the cancer team if the patient:**

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

# Constipation

Constipation is the infrequent or difficult passage of hard stool (poop), which often causes pain and discomfort. It's caused by too little fluid or not enough movement in the bowel. Lack of activity, weakness, ignoring the urge to move your bowels, 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 often helpful.
- Eat more high-fiber foods every day, 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, until the constipation is gone.
- 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. Ask your cancer team before using stool softeners or laxatives.
- Go to the bathroom as soon as you have the urge.
- Keep track 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 make bowels move.
- Encourage extra fluids.
- Help keep a record of bowel movements.
- Offer high-fiber foods, such as whole grains, dried fruits, and bran.
- Ask the cancer team before using laxatives.

### **Call the cancer team 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.”)
- Hasn’t moved bowels in 1 or 2 days after taking laxative
- Has belly cramps or vomiting that doesn’t stop

## Depression

Feelings of depression are common when patients and family members are coping with cancer. Sadness, anger, grief, and many other feelings are common, too. 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 is a more serious illness that can cause people to feel more distressed. Clinical depression makes it harder for a person to function and follow treatment plans. It happens in about 1 in 4 people with cancer, but it can be treated. People who have had depression before 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 the patient and encourage them to get help when symptoms are noticed. Patients rarely have symptoms of anxiety and depression at the same time, but it can happen. (See the section called “Anxiety, fear, and emotional distress.”)

Treatments for depression in people with cancer can 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

If someone has 5 or more of the symptoms below for 2 weeks or longer or the symptoms are severe enough to hinder normal functioning, the person should be evaluated for clinical depression by a qualified health professional or mental health specialist:

- 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 (can’t sleep, early waking, or oversleeping)\*
- Tiredness or less energy almost every day\*
- Other people notice that you’re 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

*\*Physical problems such as tiredness, poor appetite, and sleep changes can also be side effects of cancer treatment, and can linger after cancer treatment is over. Ask your cancer team about the possible causes of these symptoms and if depression might be a factor.*

### What the patient can do

- Talk about feelings and fears that you or family members have. It’s OK to feel sad, angry, and frustrated, but don’t take it out on those close to you.
  - Listen carefully to each other.
  - Decide together what you can do to support each other.
  - Encourage, but do not force, one another to talk.
- Seek 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.)



- Ask about treatments for anxiety or depression.
- Consider working with a professional counselor to deal with the changes in your life.
- Be sure your cancer team has a list of all the drugs you are taking before antidepressants are started.
- Take all medicines as prescribed.
- Expect antidepressants to take at least 2 to 4 weeks to work. Sometimes, stimulant drugs are used during this time to relieve symptoms.
- Let your cancer team know if you have side effects after starting an antidepressant.
- Avoid alcohol while on an antidepressant unless you check with your cancer team.
- 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 their fears and concerns.
- Do not force the patient to talk before they are ready.
- Listen carefully without judging the patient's feelings or your own. It's OK to point out and disagree with self-defeating thoughts.
- Don't tell the person to "cheer up" or "think positively."
- Decide together what you can do to support each other.
- Don't try to reason with the person if fear, anxiety, or depression is severe. Talk with the cancer team about medicines and other kinds of help.
- If needed, help make the appointment for evaluation or treatment and take or go with the patient.
- Engage the person in activities they enjoy.
- If the patient starts antidepressants, encourage them to continue treatment until symptoms improve (which may take 2 to 4 weeks). Talk to the person who prescribed the medicine about different treatment if symptoms don't improve by then.
- Reassure the depressed person that with time and treatment, they'll 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 things you enjoy.
- Consider getting support for yourself through groups or one-on-one counseling.

### **Call the mental health provider or the cancer team if the patient:**

- Has thoughts of suicide, or can't stop thinking about death
- Behaves in such a way that you're concerned about their safety
- Can't eat or sleep and isn't interested in their usual activities for several days
- Has trouble breathing, is sweating, or feels very restless

Also see the section, "Anxiety, fear, and emotional distress." For more on depression, visit [www.cancer.org](http://www.cancer.org) or call us at 1-800-227-2345.

## **Diarrhea**

Diarrhea is the passage of loose or watery stools 3 or more times a day with or without discomfort. It happens when water in the intestine isn't being absorbed back into the body for some reason.

Sometimes, diarrhea can be caused by an overflow of intestinal liquids around stool (poop) that's partly blocking the intestine. This is called impaction. Other causes can include chemotherapy; radiation therapy to the belly; medicines; infections; surgery; liquid food supplements that are too concentrated with 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 or apricot 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 small meals often. Don't eat very hot or spicy foods.
- Avoid greasy foods, bran, raw fruits and vegetables, and caffeine.
- Avoid pastries, candies, rich desserts, jellies, preserves, and nuts.
- Don't 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.
- Keep track of 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.
- 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 anal discomfort.
- Take medicine for diarrhea as prescribed.
- 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 cancer team should be called.
- Ask before using any over-the-counter diarrhea medicine.
- Check the anal area for red, scaly, broken skin.
- Protect the bed and chairs from being soiled by putting pads with plastic backing under the patient.

## Call the cancer team 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 belly pain or cramps for 2 days or more
- Does not urinate (pee) for 12 hours or more

- Does not drink liquids for 24 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's important to exercise as much as you can. 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 cancer team about exercises that you can safely do, and then set goals for slowly increasing your 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.
- Talk with your cancer team about the kind of exercise you can do to help reduce tiredness and give you more energy.
- If you must stay in bed, do range-of-motion exercises as instructed. In *active* range of motion, you move a joint without any help from others. *Passive* range of motion is when someone else moves it for you. Either type of range-of-motion exercises can be done in bed. Try not to move joints in a way that causes pain.

### What caregivers can do

- Go with the patient on walks or other exercise outings.
- Encourage the patient to do as much as they can for themselves.
- Ask about range-of-motion exercises if the patient has trouble getting out of bed. Remind the patient to do active range-of-motion exercises several times a day, if they can. If they can't, you can learn to help the patient with passive range of motion exercises.

## **Call the cancer team if the patient:**

- Gets weaker, starts losing their 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 their 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 they can fall off the toilet, slip in the bathtub or shower, or lose their balance as they're 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 cancer team and your caregivers know. They'll want to help prevent future falls, and might need to check you for injuries.
- If you have trouble walking, ask about a home health nursing visit. Home health nurses may be able to make your home safer for you. They also have ways to help you walk more safely.
- If a walker or wheelchair is recommended, keep it by the bed or next to where you sit. Use it every time you get up, even for short trips.

### **What caregivers can do**

- When the patient needs to get out of bed, first sit them on the side of the bed for a minute or so. This will help if changing position makes them feel dizzy or unsteady.
- If the patient is unsteady, help them walk.
- If the patient feels light-headed, stay with them when they go 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, place a commode near the bed, or put 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 about a home health nursing 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 they've fallen until you can find out if there are serious injuries. If the patient isn't breathing, call emergency services (911) unless the patient is in hospice or has a Durable Power of Attorney for Health Care that states they do not wish to be revived.
- If the patient is unconscious, bleeding, or has fluid draining from the mouth, ears, or nose, call the cancer team or 911 right away.
- If the patient can answer you, ask if they have any pain.
- Check the patient's head, arms, legs, and buttocks for cuts and bruises, and look to see if anything 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 can't move the patient, make them as comfortable as possible until help comes.
- If the patient is not in pain and isn't bleeding, help them back to a bed or chair. (If possible, get help moving the patient.)

### **Call the cancer team if the patient:**

- Notices new weakness, numbness, or change in mental status (such as if the patient is confused, doesn't know where they are, becomes forgetful, or isn't making sense)
- Gets weak or unsteady enough that a fall is likely
- Is not breathing
- Is 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 they normally do or want to do. Cancer treatment fatigue is different from that of everyday life. It's the most common side effect of cancer treatment. Fatigue related to cancer treatment can appear suddenly and can be overwhelming. It's 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 their 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 (lack of) and dehydration," "Anemia," "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 how you look
- Feeling tired even after sleeping
- Trouble thinking or concentrating
- Trouble finding words and speaking

### What the patient can do

- Balance rest and activities.
- Tell your cancer team 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.
- Ask your cancer team to help you with an exercise program to help reduce fatigue.
- Get enough rest and sleep. Short naps and rest breaks may be needed.

- Remember that fatigue caused by treatment is short term and that energy often returns slowly 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 (such as fish, meat, eggs, cheese, milk, nuts, peas, and beans), and drink about 8 to 10 glasses of liquid a day, unless your cancer team gives you other instructions.
- See the section called “Exercise.”

## What caregivers can do

- Help schedule friends and family members to prepare meals, clean the house, do yard work, or run errands for the patient. You can use websites that help organize these things, or ask a family member to look into this for you.
- Try not to push the patient to do more than they are able to.
- Help the patient set up a routine for activities during the day.

## Call the cancer team 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 can’t think clearly
- Has trouble sleeping at night
- Has fatigue that keeps getting worse
- Feels out of breath or has a racing heartbeat after only a small activity

## Fever

Fever is a body temperature of 100.5° F or higher (when taken by mouth) that most often goes up and down over the course of a day. Fever is usually caused by an infection. 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 fight invading germs. 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 “Infection, increased risk.”) You can buy an easy-to-use oral thermometer (one made to take your temperature by mouth) at any drugstore so you can check 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 belly pain
- Burning or pain when urinating (peeing)
- Sore throat
- The patient is confused, becomes forgetful, isn't making sense, or can't tell you where they are. (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 can't hold a thermometer in your mouth, hold it under your arm, in your armpit.
- Keep a record of temperature readings.
- Drink a lot of liquids (such as water, fruit juices, Popsicles, and soups).
- Get enough rest.
- Use a cold compress on your forehead if you feel hot.
- Take acetaminophen (Tylenol<sup>®</sup>) or other medicines for fever only if you've been told 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 the mouth or in their armpit. (Do not take the temperature rectally unless you've been told it's OK.)
- Offer extra fluids and snacks.
- Help the patient take their medicines on schedule.
- To help prevent fevers and infections, encourage visitors who have a fever, diarrhea, a cough, or the flu to visit the patient only by phone until they are well again.

### **Call the cancer team if the patient:**

- Is confused, doesn't know where they are, becomes forgetful, or isn't making sense (See the section called "Confusion.")
- Has a temperature of 100.5° F or higher when taken by mouth
- Has 2 or more of the symptoms listed in the "What to look for" section
- Has a fever that lasts more than 24 hours (or goes away and comes back over 24 hours)
- Has shaking chills
- Cannot take in fluids

## Fluids (lack of) and dehydration

Everything in the body contains fluid (water). The human body must have a certain amount of liquid, and not having enough can be serious.

Fluid balance means that the body's fluids are properly regulated and in the right places. Swelling is mostly caused by too much water in the body. (See the section called "Swelling.")

Dehydration is not having enough water in the body or not having enough fluid where it's needed in the body. Keep in mind that fluid comes from both food and drink, so a person who isn't eating must drink more to make up the difference.

### What to look for

- Dry mouth and lips

- Thirst
- Dizziness, weakness, constipation (See the section called “Constipation.”)
- Trouble swallowing dry food
- Dry, sticky mouth that makes 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.”)
- Rapid weight loss (See the section called “Weight changes.”)
- Little or no urine
- Fatigue (See the section called “Fatigue.”)
- Sunken eyeballs
- Poor appetite and no thirst (Dehydrated people often feel less hungry and thirsty.)

## 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.
- Use 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.
- Fill a small cooler with juice boxes, bottled water, or other drinks and keep it next to you, if it’s tiring to get up.
- Suck 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 they can.

- Include moist foods, soups, and fruit smoothies (made with ice in a blender) as snacks.
- Watch the urine output (pee) to see if it gets dark or the patient stops passing urine.
- Check with the patient often to be sure they haven't become confused.
- Stand nearby when they get up, in case they get dizzy or faint.

### **Call the cancer team if the patient:**

- Can't take in or hold down liquids
- Has vomiting, diarrhea, or fever that last for more than 24 hours
- Has urine that's either very dark or only comes in a small amount, or if there's no urine for 12 hours or more
- Becomes dizzy or feels faint when standing up
- Becomes confused or disoriented

## **Grooming and appearance**

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

Along with routine hygiene, you might 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 or putting on make-up, and combing your hair, even if you must stay in bed.
- If you'll need a wig or toupee, see the section called "Hair loss."
- Pamper yourself. Paint your nails, or buy something that makes you feel good. (Check with your cancer team first, especially before getting manicures, pedicures, or waxing in salons or spas.)
- Nails may start to separate from the nail bed during treatment. Keeping them short so that they don't catch on things may help.
- Nails may discolor during cancer treatment. Nail polish is usually OK, but check with your cancer team and plan to use a mild (non-acetone based) polish

remover. Don't use artificial or glue-on nails during and for a few months after treatment.

- Use clean tools to gently cut, clean, and file nails. Push cuticles back rather than cutting them.
- Protect hands and nails with household gloves during chores to reduce exposure to soaps and cleaning agents. Use moisturizing creams after hand washing.
- Use an electric razor for routine shaving to prevent nicks and cuts.
- Exercise each day, as much as you can manage comfortably. Ask about an exercise plan. (See the section called "Exercise.")
- Get enough rest.
- Keep up with regular mouth care. But you should talk with your cancer team before setting up dental cleanings or other procedures during treatment.

## What caregivers can do

- When the patient is strong enough, encourage them to go on short outings they enjoy.
- Help the patient keep a supply of their preferred toiletries, lotions, and grooming supplies on hand.

## Hair loss

Hair is constantly growing, with old hairs falling out and being replaced by new ones. Some cancer treatments make people 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's normal for both men and women to feel upset about losing their hair. It helps to know that hair grows back, and you can take steps to make its loss less of a problem for you.

Hair is lost when chemotherapy drugs damage hair follicles, making hair fall out. It can be hard to predict which patients will lose their hair and which ones won't, 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 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 is going to happen, it most often starts within 2 weeks of treatment and gets worse 1 to 2 months after starting therapy. Your scalp may feel very sensitive to washing, combing, or brushing. But hair often starts to grow back even before treatment ends.

## 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 – you might need a smaller wig 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.
- Wigs may be partially or fully covered by your health insurance. If so, ask for a prescription for a “cranial prosthesis.” Do not use the word “wig” on the prescription.
- Get a list of wig shops in your area from your cancer team, other patients, or from the phone book. You can also order the American Cancer Society’s “*tlc*” *Tender Loving Care*<sup>®</sup> catalog (for women with hair loss due to cancer treatment) by visiting [www.tlcdirect.org](http://www.tlcdirect.org) or by calling 1-800-850-9445.
- If you’re going to buy a wig, try on different styles until you find one you really like. Consider buying 2 wigs, one for everyday use and one for special occasions.
- Synthetic wigs need less care and styling than human hair wigs. They also cost less and may be easier if you have low energy during cancer treatment.
- Some people find wigs are hot or itchy, and use turbans or scarves instead. Cotton fabrics tend to stay on a smooth scalp better than nylon or polyester. Wear a hat or scarf in cold weather to cover and stay warm.
- Use a broad-spectrum sunscreen with a sun protection factor (SPF) of 30 or higher and a hat to protect your scalp from the sun.
- Be gentle when brushing and washing your hair. Use a wide-toothed comb.
- Hair loss might be somewhat reduced by avoiding too much brushing or pulling (which can happen while making braids or ponytails, using rollers, blow drying, or using curling or flat irons).
- Wear a hair net at night, or sleep on a satin pillowcase to keep hair from coming out in clumps. Be gentle with eyelashes and eyebrows, which might also be affected.
- If the thought of losing your hair bothers you, you might choose to cut your hair very short or even shave your head before it starts falling out.
- When new hair starts to grow, it may break easily at first. Avoid perms and dyes 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. There's not a lot of research on managing hiccups, but here are some of the things people have found useful.

## 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 your mouth and then swallow.
- Avoid forcing yourself to eat.

## What caregivers can do

- Watch the patient to be sure that they're 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 cancer team if the patient:

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

# Infection, increased risk

Many cancer treatments and cancers can cause changes in your blood counts. A low white blood cell (WBC) count can put you at higher risk of infection. You may hear this called *neutropenia*, or be told that you are *neutropenic*.

The WBC count measures your body's ability to fight infection. A normal WBC count is about 5,000 to 10,000. When your WBC count is low, you'll need to watch for signs of infection so that you can get treatment right away.

## What to look for

- Temperature of 100.5° F or higher when taken by mouth
- Any new area of redness, tenderness, or swelling
- Pus or yellowish discharge from an injury or other location
- New cough or shortness of breath
- New abdominal (belly) pain
- Shaking chills that may be followed by sweating
- Burning or pain when passing urine (peeing)
- 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) for a fever only after getting the OK from your cancer team.
- Keep warm.
- Take antibiotics or other medicine as prescribed.
- Drink fluids, but don't force more than you can tolerate.
- Avoid anything that can cause cuts, scrapes, or other breaks in the skin.
- Wash cuts and scrapes with soap and water every day, apply antibiotic ointment, and keep them covered until healed.
- Wash your hands after using the bathroom or visiting public places. Use hand sanitizer when you don't have soap and water.
- Avoid crowds, and don't visit with people who have infections, coughs, or fevers.
- If you eat raw foods, wash them carefully and peel them to avoid germs.
- Brush your teeth twice a day, and floss once a day (unless you were told not to floss).
- Drink 2 to 3 quarts of liquid each day, if OK with your cancer team.



## What caregivers can do

- Watch for shaking chills, and check the patient's temperature after the shaking stops.
- Check the patient's temperature using a thermometer in the patient's mouth or under the armpit. (Do not take a rectal temperature.)
- Encourage visitors who have diarrhea, fever, cough, 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 cancer team if the patient:**

- Has a temperature of 100.5° F or higher when taken by mouth
- Has shaking chills
- Feels or seems “different” to others
- Cannot take in fluids

Please see the section called “Fever.”

## Itching

Itching can keep you awake and cause restlessness, anxiety, skin sores, and infection. Common causes of itching in people with cancer include dry skin, allergies, side effects of medicines, and cancer treatment. Other illnesses and certain kinds of cancer can also cause itching.

### What to look for

- Dry, red, rough, flaky skin
- A yellowing of the skin or of the whites of eyes
- Rash or bumps
- Scratch marks
- Skin sores
- Scratching when you don't notice it

## What the patient can do

### **To soothe the skin**

- Ask your pharmacist about skin creams that don't contain alcohols or fragrances. Apply them 2 to 3 times a day, especially after a bath when the skin is damp. You can try calamine lotion (Caladryl<sup>®</sup>) or witch hazel if they soothe the itching, but note that they can dry the skin. Check with your cancer team if this doesn't work.
- Bathe in warm water instead of hot.
- 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, after-shaves, or 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.
- Keep your room cool (60° to 70° F) and well ventilated to avoid sweating.
- Drink plenty of water and other fluids.
- Get enough rest. Ask about medicine (antihistamines) if itching keeps you awake.

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

- Apply cool, wet packs (such as crushed ice in a plastic bag that's wrapped in a damp 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.
- Wear loose, soft clothing.
- Distract yourself with music, reading, and the company of others.
- Take medicines for itching as prescribed.

## What caregivers can do

- Try using mild, unscented detergents to wash the patient's clothes and bedding.
- If the patient scratches in their sleep, ask them to wear clean cotton gloves to reduce the chance of skin damage.

### **Call the cancer team if the patient:**

- Has itching that does not go away after 2 or more days
- Develops yellowish skin or has urine (pee) the color of tea
- Scratches skin until it's open or bleeding
- Has a rash that gets worse after creams or ointments have been used
- Has blisters, bright red skin, or crusts on the skin
- Has foul-smelling drainage or has pus coming from the skin
- Becomes very anxious and restless (can't 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 signs 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 leg or foot cramps. Dehydration, certain drugs, overuse, 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 imbalances in blood chemistry.

### What to look for

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

### What the patient can do

- Keep warm, and change position often.
- If you are bed-bound, use a bed cradle to protect the legs and feet from the weight of the blankets. A bed cradle is a support at the end of the bed that holds the sheets and blankets 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.
- Gently stretching the muscles before lying down may help prevent cramping.
- Tell your cancer team about the cramps. They may be able to give you medicine to help prevent or reduce them.
- Apply heat to legs when they cramp, if it's OK with your cancer team. Ask about what kind of heat to use and how long you should use it.
- Massage the leg, if it's OK with your cancer team.
- When you have a cramp, contract the opposite muscle group. Sit up or stand up 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 cancer team's instructions for correcting dehydration, or imbalances in calcium, potassium, or phosphorus.

## What caregivers can do

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

## Call the cancer team if the patient:

- Has cramping that's 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 often caused by mouth sores, gum (periodontal) disease, or by a low platelet count (cells that help the blood clot). Low platelet counts can be a side effect of chemo or radiation treatment. (See the section called "Bleeding or low platelet count.")

Everyday actions such as brushing or flossing teeth can cause bleeding. Side effects of chemo or radiation can include dry mouth or small mouth sores, 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
- Blood oozing from mouth

## What the patient can do

- Rinse your mouth gently with ice water every 2 hours.
- Suck on ice chips. (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 hot water to soften the bristles even more.
- Use soft foam mouth swabs or gauze wrapped around a Popsicle stick or tongue depressor to clean 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, smooth, and high in calories and protein. Refrigerated soft foods, such as ice cream, applesauce, puddings, and yogurt, can help because cold helps to slow the bleeding.
- Puree hard foods, such as apples, pears, etc., in the blender.
- Avoid hot drinks, such as coffee and tea. Heat enlarges blood vessels and can make bleeding worse.
- Put cream or salve on your lips to prevent dryness.
- If you wear dentures, keep them out of your mouth, especially if they don’t 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, sharp or crunchy foods (such as chips or crackers), and foods with hard coatings.
- Freeze a few wet tea bags, and have the patient press one on any bleeding area.

### **Call the cancer team 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's not enough saliva. It can be caused by mouth-breathing, or it could be a side effect of medicine, radiation treatment to the head and neck, or dehydration. (See the section called "Fluids (lack of) 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 (mouth-breathing dries out the mouth and throat)
- Burning tongue
- Bits of food or other matter on the 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 and spit. Do not swallow it.
- Sip liquids with meals to moisten foods and help with swallowing.
- Add liquids (such as gravy, sauce, milk, and yogurt) to solid foods.

- Try ice chips, sugarless hard candies, and sugarless chewing gum.
- Keep cold water nearby for frequent sips between meals and mouth rinses.
- Rinse or spray mouth often using artificial saliva, which is sold in drugstores.
- Use petroleum jelly, cocoa butter, or a mild lip balm to keep lips moist.
- Avoid hot, spicy, or acidic foods.
- Avoid chewy candies, tough meats, and hard raw fruits or vegetables.
- Avoid alcohol, including 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.
- Keep cold water nearby for frequent sipping.
- Help the patient track their fluid intake, and encourage them to take in 2 to 3 quarts of liquid each day, if the cancer team approves. Ice, ice cream, sherbet, Popsicles, and gelatin count as liquids.

## Call the cancer team if the patient:

- Has a dry mouth for more than 3 days
- Can't take medicines or swallow pills
- Can't 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 use, 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 (lack of) and dehydration.")

## What to look for

- Inside of mouth and gums look red, shiny, or swollen
- 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
- Blood in the mouth
- Soft, whitish patches or pus in the mouth
- Increased mucus in the mouth
- Soreness or pain in the mouth or throat
- Feeling of dryness, mild burning, or pain when eating hot and cold foods

## What the patient can do

- Check your mouth twice a day using a small flashlight and a padded Popsicle stick. If you wear dentures, take them out before you check your mouth. Tell your cancer team 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 you're awake, or at least twice a day unless you've been given other instructions:
  - 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 it with hot water during brushing. If the toothbrush hurts, use a Popsicle stick with gauze wrapped around it. Or get soft foam mouth swabs to clean your teeth. (You can buy these at a drugstore.)
  - Rinse toothbrush well in hot water after use and store in a cool, dry place.
  - Use a non-abrasive toothpaste that contains fluoride. Note that whitening toothpastes may contain hydrogen peroxide, which can irritate sore mouths.
  - 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.
  - 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 mixed with  
2 cups water

**or**

1 teaspoon salt and  
1 teaspoon baking soda mixed with  
1 quart water

- Avoid store-bought mouthwashes, which often contain alcohol or other irritants.
- If you normally floss, keep flossing at least once a day unless you're told not to do so. Tell your cancer team if this causes bleeding or other problems. If you don't usually floss, ask before you start.
- Keep your 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 cancer team approves.
- To promote healing, ask 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 letting the paste sit for 15 to 20 minutes.
- If mouth pain is severe or makes it hard to eat, ask about medicine that can be swished 15 to 20 minutes before meals or painted on a painful sore with a cotton swab before meals. If this doesn't work, you may need something stronger. Ask about other medicines to relieve pain.
- Eat chilled foods and fluids (such as Popsicles, ice chips, frozen yogurt, sherbet, or ice cream).
- Eat soft, moist foods that are 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.
- Don't eat very salty, spicy, or sugary 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 the patient wears dentures, remove them before looking.
- Offer liquids with a straw, which may help bypass the sores in the mouth.
- Offer soft foods. Mash or puree foods in a blender to make them easier to eat.
- Try coating mouth sores with Anbesol<sup>®</sup> or Orajel<sup>®</sup> before meals to numb them during eating.
- Offer pain medicines 30 minutes before mealtime.

### **Call the cancer team if the patient:**

- Has redness or shininess in their 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
- Can't take medicines because of mouth sores

## 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 happen when a person isn't even thinking about food. And a person can vomit even if they haven't eaten anything. Sometimes they vomit even if they haven't had any nausea.

Nausea or vomiting can be caused by eating something that disagrees with you, by bacteria in food, by infections, or by radiation or chemo treatments for cancer. Many people have little or no nausea or vomiting with these treatments. For others, just thinking about going for one of the treatments can cause nausea or vomiting. Cancer by itself can cause nausea and vomiting.

Frequent vomiting can be dangerous because it can lead to dehydration. See the section called “Fluids (lack of) and dehydration.” It can also lead to inhaling food or liquids, which can cause choking and other problems. Talk with your cancer team about what's 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**

- 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 you can see through, such as ginger ale, apple juice, broth, tea, etc.) Also try Popsicles or gelatin.
- Suck on hard candy with pleasant smells, such as lemon drops or mints, to help get rid of bad tastes. (Don't eat tart candies if you have mouth sores.)
- Eat bland foods, such as dry toast and crackers.
- 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.
- Eat 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.
- 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 TV program, or the company of others.
- Tell your cancer team about the nausea, because there are many drugs that can help it.

- Take your anti-nausea medicine at the first signs of nausea to help prevent vomiting.
- While waiting for your nausea medicine to work, relax and take slow, deep breaths.
- If you have nausea just before chemo or other appointments, 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 won't inhale the vomit.
- Ask that medicines be prescribed in the form of dissolving tablets or suppositories, if possible. To prevent vomiting, take the medicine at the first hint of nausea.
- Try liquids in the form of ice chips or frozen juice chips, which can be taken slowly.
- After vomiting stops, start taking in 1 teaspoon of cool liquid every 10 minutes. Gradually increase to 1 tablespoon. 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.
- Use plastic forks and spoons rather than metal ones, which may cause a bitter taste.
- If the patient is vomiting over a period of days, weigh them at the same time each day to help decide if dehydration is getting severe.
- Ask 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 cancer team if the patient:**

- Might 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 can't eat for more than 2 days
- Can't take medicines
- Becomes weak, dizzy, or confused
- Loses 2 or more pounds in 1 to 2 days (This means they are losing water quickly and might be getting dehydrated.)
- Develops dark yellow urine (pee) and doesn't have to urinate as often or as much

## Pain

When people say they are having pain, it usually means they're hurting somewhere. But it can also mean that they just can't get comfortable. They could be feeling bad in general, not in any one place. The feeling of pain can be worse if a person is sad, anxious, or depressed. Some people have a hard time talking about their pain. It's important that you tell your cancer team about any pain you have.

Even severe pain can be controlled very well by combinations of medicines that can be taken by mouth. Pain medicines work best for chronic (long-term) pain if they are used on a regular schedule before the pain becomes severe. It takes more medicine to control severe pain than milder pain, so it's best to tell your cancer team right away. You'll want to treat pain when it first starts and regularly after that. If the cause of the pain can be treated, the need for medicine will slowly decrease or disappear as the cause is treated.

If you have pain from cancer that has spread or other long-term cancer pain, it can exhaust you. This type of chronic or long-term pain can 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. Always tell your cancer team how well your pain is controlled so that medicines and doses can be adjusted as needed.

## What to look for

- Pain that doesn't seem to go away or that goes away and comes back before your next dose of pain medicine is due (This might mean that your medicine plan needs to be changed.)
- Trouble sleeping
- Lack of interest in things you used to enjoy

- New areas of pain or a change in your pain
- Less ability to move around or do things

## What the patient can do

- Talk with your cancer team about your pain – where it 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 cancer team 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 cancer team if this schedule needs to be adjusted.
- As the pain is relieved with medicines, increase your activity level.
- Don't wait until the pain is severe before taking medicine for breakthrough pain.
- Avoid suddenly stopping any of your pain medicines. Instead, reduce the dose slowly as the pain decreases. Ask your cancer team before you do this, or if you have questions.
- Some people feel nauseated even when they're taking the right dose of pain medicine. If your pain medicine makes you feel sick, ask your cancer team about changing it or trying something to control the nausea.
- Some pain medicines make you sleepy or dizzy. This often gets better 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 pain medicines are normally given laxatives or stool softeners to prevent constipation, a common side effect.
- Keep track of any other side effects you notice. Discuss them with your cancer team.
- Do not crush or break your pain pills unless you get the OK from your cancer team. If medicines are in time-release form, taking broken pills can be dangerous.
- If pain medicines are not keeping your pain under control, ask your cancer team 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 can't be refilled by phone, so you'll need a written prescription.

## What caregivers can do

- Watch the patient for signs of 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 might also help some types of pain.
- Watch for confusion and dizziness, especially after starting a new medicine or changing the dose. Help the patient walk until you know they can do it alone safely.
- Suggest enjoyable activities to distract the patient.
- 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 them track when pain medicines are due to avoid over- or under-dosing.
- Help the patient remember to take stool softeners or laxatives suggested to prevent constipation. (See the section called "Constipation.")
- If the patient is having trouble taking pills, ask the cancer care team about medicines that come in liquids, lozenges, suppositories, skin patches, or other forms.
- Check with the cancer team before you crush or dissolve pain pills to make them easier to swallow. Some pills can cause a dangerous overdose if broken.
- Talk with the cancer team 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 they are on, including pain medicines.
- If you help the patient use 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 pain medicines away from others, especially children and pets.
- When you are caring for someone with pain, plan time for activities you enjoy and take care of yourself. A support group for family members may be helpful.

## **Call the cancer team if the patient:**

- Has new or worse pain
- Can't take anything by mouth, including the pain medicine
- Doesn't get pain relief, or if the relief doesn't last long enough
- Has trouble waking up, or if you have trouble keeping them 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 pass urine [pee])

For more on pain management, call the American Cancer Society at 1-800-227-2345. Visit [www.cancer.org](http://www.cancer.org) to find more pain information.

## **Prostheses**

Prostheses (pross-THEE-sees) are man-made substitutes for missing body parts. ("Prostheses" refers to more than one; just one is called a prosthesis, pronounced pross-THEE-sis.) 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 naturally as possible.

There are many different types of prostheses. Some are worn on the outside of the body and can be put on and taken off (external prostheses), and others are implanted during surgery. People with cancer may need prostheses for the breasts, legs, or testicles, or an implant for the penis. Wigs used to cover the short-term hair loss that happens with some kinds of chemo can be thought of as prostheses, too. (See the section called "Hair loss.")

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

- Before surgery, ask your cancer team about prostheses.
- Find out if you might need a prosthesis. If so, ask if it can be placed or implanted during surgery.
- Make sure that you get a prescription for the prosthesis, because it may be covered by health insurance (this includes wigs).

### **Breast prostheses**

- Wear a breast form (that fits into your bra).



- Small prostheses (“equalizers”) are available for women who have had just part of a breast removed.
- Nipple prostheses can be added during surgery when the nipple can’t 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. You can also find custom-made forms if needed.
- Shop around to find the best fit and the right price.
- Prostheses may feel heavy, but they should stay in place when you move and feel comfortable. They should also look like your natural shape and feel a lot like your other breast when you touch them.
- Ask if the prosthesis absorbs sweat, and find out how to clean and care for it.
- 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 medical team or physical therapist. The permanent prosthesis can be fitted after you are stronger.
- Limbs that help balance your appearance (but don’t actually work) can be used if you can’t use a permanent working prosthesis.
- Ask questions about how to care for the surgical site and the prosthesis. If you’re uncomfortable, or have redness or blisters, talk with your cancer team. If the prosthesis needs to be adjusted, take it back to be fixed. Don’t try to do it yourself.

## **Testicular implant**

- A testicle-shaped form can be put in the scrotum 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 to your cancer team 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.
- Different types are available. Discuss options and what type is best for you with your partner and with your cancer team. See the section called “Sexuality” for more information.

## **Call the cancer team 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 disrupts its structure. The wound may be under the skin, may affect only the skin surface, or might affect the skin on the surface and beneath it. An incision (cut) from surgery is a wound. A wound also can be caused by a fall or accident, tumor growth, pressure on bony areas, or radiation therapy. Proper care for a wound is important to protect it 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
- Bleeding
- Swelling
- Drainage or pus
- Warmth or heat at the affected area
- Pain or tenderness

## What the patient can do

- Wash your hands well before and after changing a 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, or use sterile, non-stick gauze. Use paper tape if you can.
- 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 the dressing change.
- Try not to put tape right on the skin. Use a “skin prep” solution to protect skin where the tape goes, 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. Don’t remove scabs.
- Eat citrus fruits, green leafy vegetables, whole grains, meat, fish, and eggs. They contain protein, vitamins, and minerals that help promote wound healing.

## What caregivers can do

- Help clean wounds or change dressings if the patient can’t do it alone. 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 instructed.
- Check for signs of infection (redness, swelling, tenderness, drainage or pus).

## **Call the cancer team if the patient:**

- Has a wound that bleeds for 15 minutes or longer
- Has a wound that looks very red around the edges and is hot or swollen
- Has more pain than usual at the wound site
- Has a bad smell coming from the wound
- Has yellow pus or greenish liquid that oozes from the wound

- Has any changes in the skin around 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 don't work properly. Seizures usually last less than 5 minutes. They are followed by sleepiness and confusion that 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 your cancer team about your seizures. Bring the person who saw your seizure with you to answer any 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 them from falling to the floor and hitting their head.
- Stay with the patient.
- Stay calm.
- Loosen any clothing around the patient's neck.
- If the patient falls to the floor, put padding (such as rolled-up clothes or towels) under their head and roll them onto their side.
- If the patient is lying on their back and you can't roll them, gently turn their head to the side if you can. Don't force any part of the body to move.
- Try to notice what type of movements the patient makes, how long the seizure lasts, and what parts of the body move with the seizure.

- Don't try to open the mouth during a seizure, even if the patient is biting their tongue. Keep your fingers and hands away from the patient's mouth.
- Don't move the patient unless they are in a dangerous location (such as near a hot radiator, glass door, or stairs).
- Once the seizure is over, cover the patient with a blanket and let them rest.
- Don't give medicines, food, or liquids until you call the cancer team and the patient is fully awake.
- If the patient is known to have seizures, use side rails and bumper pads on their bed. Be sure someone is with the patient when they're walking or sitting in a chair.
- Give anti-seizure medicine as prescribed.

### **Call the cancer team if the patient:**

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

## **Sexuality**

Sexuality includes holding hands, special looks, hugging, kissing, etc. It's not just the sex act. This section addresses side effects of different treatments that affect your sex life and ways to relieve some common problems. It's important that you talk about any questions or concerns with your cancer team, and even more important that you talk with your partner. Remember that warmth, caring, and physical and emotional closeness are as necessary and rewarding as anything else in your relationship.

Chemo, radiation, and some surgery for cancer can affect the fertility of men and women – some people won't be able to have children. In women, treatment may cause early menopause. Men might not be able to make normal sperm. It's 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 a few weeks of ending treatment. Avoid pregnancy during chemo or radiation. Find out how long you should wait after your specific type of treatment before trying to conceive. Ask what you should expect and talk about any plans to have children. If you want children later, do this **before** treatment begins.

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

- Realize that your sexual desire may decrease for a lot of reasons. The fear of having cancer, worries about treatment, and the effects of treatment itself are just a few. Chemo can sometimes make you very tired or sick. Radiation

therapy to the pelvis or genital area can cause pain during sex. Hormone treatments and the removal of the ovaries or testicles will change your body's hormone levels. All of these things can affect desire or make you less able to have sex.

- Talk with your partner about your feelings and concerns.
- Wait until you feel ready for sexual activity. Don't push yourself.
- Tell your partner you're ready to try sexual contact when you feel able to. Don't 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 "Infection, increased risk" for more information.) Check with your cancer team to see if this is an issue for you.
- Enjoy other forms of closeness, such as touching, caressing, and holding each other.
- Know that you cannot give your partner cancer.
- Try other things such as using your hands or mouth, stroking, fondling, or kissing if your usual sexual activity is uncomfortable. You can also try 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 getting too tired.

## **Men**

- Before you get chemo or radiation to the genital area, ask about saving sperm in a sperm bank if you think you might want to father children later.
- Around half (40% to 60%) of men have some trouble getting an erection after radiation to the genital area. Impotence (inability to get a strong enough erection) usually does not happen right after radiation treatment, but can develop slowly 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 about getting your serum testosterone levels checked to see if hormone replacement therapy might help you (although not every man with cancer can take testosterone). Ask about other medicines or treatments that might 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 semen may take months or years, or may not happen at all. Keep in mind that 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 isn’t harmful or worrisome, but should be reported to your cancer team.
- Sometimes, you may accidentally pass a little urine (pee) during sex. There’s no need for concern about this. Urine is normally sterile and won’t harm your partner.
- Use romantic dinners, erotic stimulation, and prolonged foreplay.
- Shower together and use sexual play.

## Women

- Pain during sex is very common after surgery for many gynecologic cancers because it can shorten or narrow the vagina. Ask your surgeon about the exact extent of your surgery and what to expect during sex. To help with this:
  - Keep the vagina from getting smaller and tighter during radiation therapy to the pelvis or vagina. You’ll 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.
  - If surgery that involves the vagina is planned, ask about vaginal dilators to use after surgery. Be sure to find out when to start using them and how.
  - Use an unscented, uncolored, water-based lubricant such as K-Y® or Astroglide® if the vagina is too dry during sex. Surgery, radiation, or hormone treatments for cancer can cause dryness.
  - Show your partner ways of touching or positioning that are comfortable to you.
  - Before you try sex with your partner, check to see if there’s any soreness in your genital area.
- Chemo can thin the vaginal wall. Slight bleeding after sex is not a major concern, but it might help to use extra water-based lubricant. Don’t use 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 cancer team if this happens.
- Chemo may cause you to stop menstruating (having your monthly periods) 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. Ask about birth control, since chemo drugs can hurt a growing fetus.
- Chemo, radiation, or surgery that removes the ovaries may cause early menopause. Ask about your chances of this happening.
- If you are likely to become infertile, ask about the possibility of freezing ovarian tissue or embryos. This requires special surgery and can be very expensive, but it can be an option for some women.

## What partners can do

- Find out how cancer and the cancer treatment are likely to affect sex with your partner. For instance, chemo can cause side effects such as fatigue. Surgery and radiation in the genital area might permanently change how the genitals look or work.
- Learn what changes to expect if the patient is taking hormones, which may affect sexual function or desire.
- Be patient during chemo or radiation. Wait until 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 their body and about sexual activity. Sometimes, people feel unattractive after cancer treatment.
- Changes to your partner's body affect how they see themselves. This affects both of you, and it's normal to grieve about these losses and changes. It may help to ask to be referred to a mental health professional if you've had 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 won't be interrupted.
- Use unscented, uncolored water-based lubricant (such as K-Y or Astroglide) if dryness makes either of you uncomfortable.
- If you are afraid of hurting your partner, talk about it with them and with the cancer team.



## Call the cancer team if the patient:

- Notices new or more pain
- Notices bleeding
- Has an unexpected change in erectile function or in the amount of semen
- Has any sexual problems or questions about 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*. We also have more on fertility concerns, such as freezing eggs or sperm before chemo. Visit [www.cancer.org](http://www.cancer.org) for more information.

## Shortness of breath

If the patient is having trouble breathing, the body might not get enough oxygen. Either the lungs can't take in enough air, or the body can't get enough oxygen through the bloodstream. A number of different problems can cause this, such as lung disorders, blocked airways, pneumonia (a lung infection), weak breathing muscles, or obesity. It can also be caused by pain, immobility, poor nutrition, stress or anxiety, allergic reactions, surgery, anemia, the side effects of chemo or radiation treatment, a tumor, fluid in the lungs, heart failure, and other problems.

### What to look for

- Shortness of breath or trouble breathing when resting, eating, or talking, or with exercise
- Chest pain
- Faster breathing
- Faster heartbeat
- Pale or bluish-looking skin, fingernail beds, and mouth
- 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're 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 you're still not breathing easier after 5 minutes, sit up on the side of the bed, with your feet resting on a stool, arms resting on an overbed table or side table with pillows on it, and your head tilted slightly forward.
- If you're coughing and spitting, note the amount of sputum and what it looks and smells like.
- Tell your cancer team 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. (See the section called "Anxiety, fear, and emotional distress.")
- If you keep having trouble breathing, ask about medicines that might help.
- If new shortness of breath starts suddenly and doesn't get better; your skin, mouth, or nail beds look pale or blue; or if you have chest discomfort, trouble speaking, dizziness, or weakness, call 911.

## What caregivers can do

- Using a watch with a second hand to check the patient's pulse, count the number of beats per minute. (If you also count the number of breaths per minute, do it without telling the patient. If the patient knows you're counting, they may slow down or speed up breathing without realizing it.)
- Check the patient's temperature to see if they have a fever.
- When the patient feels short of breath, remove or loosen tight clothing.
- Have the patient sit up in a resting position that feels comfortable to them.
- Remind them to breathe in slowly and deeply, then exhale slowly.
- Remove the patient from extreme temperatures, especially heat, which can make it harder to breathe.
- Note when the patient gets out of breath. (During normal activity, while talking, or when they are at rest?) Also note if it happens when they're 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 medicines or inhalers prescribed for shortness of breath.
- If home oxygen is prescribed, be sure you know how to set it up, use it safely, and what flow rate to use. (Do not change the flow rate without first talking to the cancer team.)

### **Call the cancer team if the patient:**

- Has trouble breathing or chest pain
- Has thick, yellow, green, and/or bloody sputum
- Develops pale or bluish skin, nail beds, or mouth; or if their skin feels cold and clammy
- Has a fever of 100.5° F or higher 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
- Starts wheezing

## **Skin color changes**

Skin changes color usually because there's something going on 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 treatment. Some color changes may improve over time, while others may be long lasting.

### **What to look for**

- Yellowish skin and/or the whites of the eyes. May also have deep orange to brown urine (pee) and/or white or clay-colored (light brown or gray-looking) stools (poop).
- Bruises or areas of blue or purple skin that have no known cause

- Very pale or blue-tinged skin, lips, or nail beds. Often with trouble breathing (See the section called “Shortness of breath.”)
- Redness or rash on skin
- Swelling in an area that’s discolored
- Itching (See the section called “Itching.”)

## What the patient can do

- Clean the skin gently with warm water, gentle soap, and a soft cloth.
- Rinse the red or rash-covered area carefully and pat dry.
- Apply water-repellent salve, such as petroleum jelly or A+D<sup>®</sup> ointment. Expose the affected skin to air whenever possible.
- Protect the affected area from heat and cold.
- Wear loose-fitting, soft clothing.
- Apply medicines prescribed for skin reactions.
- Protect all of your skin from the sun. (For instance, wear a wide-brimmed hat, sunglasses, and long-sleeved shirts when outside.)
- Apply broad-spectrum sunscreen with an SPF of 30 or higher on any skin exposed to the sun. Re-apply every 2 hours if in the sun, and after bathing or sweating.

## What caregivers can do

- Keep track of any new medicines, soaps, detergents, or 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 cancer team if the patient:**

- Develops yellowish skin or whites of the eyes (or has urine that stays dark or orange for a day or more and/or stool that looks white or clay-colored for 2 or more bowel movements)
- Has severe itching (See the section called “Itching.”)

- Has bruises that don't go away within a week, or new bruises showing up 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's often caused by not having 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 treatment.

### **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 joints, such as knuckles or elbows

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

- Add mineral or baby oil to warm bath water, or put it on after showering while skin is still damp. (This can make you and the floor slippery, so hold onto something when you're moving around barefoot.)
- Wash with cool or warm water, not hot water.
- Avoid scrubbing the skin during showers or baths. Gently pat skin dry after bathing.
- Put on moisturizing, alcohol-free 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 you've been told it's OK to do this.
- Protect your skin from cold and wind. Avoid hot water and heat, especially dry heat.

### **What caregivers can do**

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

## **Call the cancer team 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, often leaving an open crater or ulcer in the skin. 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 sheets rub against them or the patient is roughly pulled up in the bed or chair.

### **What to look for**

- Cracked, blistered, scaly, or broken skin
- An open sore on the skin's surface or in the 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)
- Red pressure points on the skin that don't go away even after the pressure is removed (can be an early sign that skin is about to break down or die)

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

- Change your 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 foam or gel seat cushions to reduce pressure.
- Choose clothing that isn't too tight or so loose that it bunches up under you.
- Protect other "pressure points" with pillows to help prevent new sores. If possible, use a pressure-reducing mattress or 3- to 4-inch foam layer over your mattress.
- Exercise as much as possible. Try to take a short walk 2 or 3 times a day. If you can't 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, nuts, or peanut butter).
- Increase fluids. (If you're not eating well, try high-calorie liquids such as milkshakes or canned liquid food supplements.)
- 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. If you're given ointments or creams, use them as directed. Report any itching, blistering, new drainage, or increase in size of the sore to your cancer team.

## What caregivers can do

- Remind the patient to change positions often, or help the patient turn every 2 hours.
- If the patient can't control their bowels and bladder, change their underwear as soon as you notice soiling. After cleaning, apply an ointment (such as A+D ointment) to keep the area dry. Sprinkle cornstarch over the ointment. Use underpads to keep the patient from soiling the bed and to make it easier to clean up. Don't use plastic underwear unless the patient is out of bed.
- If the skin has an open sore, ask about special dressings to help protect it.
- If the patient can't get out of bed:
  - Keep the bottom sheets pulled tight to prevent wrinkles.
  - Keep the head of bed flat or no higher than a 30° angle.
  - Sprinkle sheets with cornstarch to reduce friction from rubbing against them.
  - Check the patient's back and sides each day to be sure that the skin looks normal. Pay special attention to pressure areas such as the tailbone, hipbones, knees, ankles, heels, shoulders, and elbows.
  - If you notice a reddened "pressure area" (an area that stays red after pressure is taken off it), keep the pressure off it as much as you can to try to prevent further breakdown. Use pillows and have the patient change position often.
- If the patient has trouble staying on their side, ask about foam wedges to help hold positions.
- Ask your cancer team if you can get a home health nurse to visit and help you make a plan to care for and prevent further skin problems.

- Ask if you can get foam, gel, or air cushions for the bed and chairs. Find out about special beds that help reduce pressure.

### **Call the cancer team if the patient:**

- Has cracked, blistered, scaly, or broken skin
- Has a sore that's getting bigger
- Has a thick or bad-smelling liquid draining from the sore
- Needs help from a home care agency for wound care and supplies

## **Sleep problems**

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

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

- Sleep as much as your body tells you to, but when you're 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 caffeine for at least 6 to 8 hours before bedtime – longer if it affects your sleep.
- Do not drink alcohol in the evening. It can keep you awake as it "wears off."
- Drink warm, caffeine-free drinks, such as warm milk or decaf tea, before sleep.
- Use a quiet setting for rest at the same time each day. Take short daytime naps if needed (less than an hour) to avoid interfering with nighttime sleep.
- Take prescribed sleeping medicine or pain relievers at the same time each night. If pain keeps you awake, see the section called "Pain."
- Have someone rub your back or massage your feet before bedtime.
- Keep sheets clean, neatly tucked in, and as free from wrinkles as possible.
- Talk with your cancer team about relaxation therapy or getting a referral to a hypnotherapist.



## What caregivers can do

- Help keep the room quiet and comfortable during sleep.
- Offer gentle backrubs or foot massages near bedtime.
- Offer a light bedtime snack.
- Let the cancer team know if the patient seems to be confused during the night.

### **Call the cancer team if the patient:**

- Is confused at night
- Can't sleep at all at night

## Stomas (or ostomies)

A stoma is a surgically created opening in the body that replaces a normal opening. It's 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 body functions.

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

- Tracheostomy (pronounced TRAY-key-**AHS**-tuh-me), or trach (trake) for short. These go into the trachea, or windpipe through the front of the neck
- Urostomy (yur-**AHS**-tuh-me) in the bladder or urinary system, through the belly
- Colostomy (kuh-**LAHS**-tuh-me) in the colon, through the belly

## What the patient can do

### **Tracheostomy**

- Use pen and paper to "speak" or communicate with others.
- Leave the outer tube of the trach in place unless you've been told otherwise.
- Clean your trach tube at least once a day as instructed.
- Suction the tube as needed or as directed.
- Wash your hands carefully before and after handling your trach to help prevent infections.
- Be careful to keep water out of the trach while bathing. A child's bib with the plastic side facing outward can be used to keep water out and let you breathe while you shower, or you can buy special protective covers.

- Do not swim, and be very cautious around bodies of water. Being in water that may get close to your neck is risky for you because water can get right into your lungs through the trach.
- Wear a scarf or shirt made of thin fabric (such as cotton) that covers the opening but lets air get through. This helps protect the trach from dust and loose fibers.
- Ask to meet with a respiratory therapist, ostomy nurse, or speech-language pathologist if you need more information.
- You may want to visit [www.theial.com/ial/](http://www.theial.com/ial/) or call 1-866-425-3678 to learn about the International Association of Laryngectomees.

## **Urostomy and colostomy**

- Gently clean the skin around your ostomy with warm water only. (You might 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 the pouch on or off.
- Apply barriers, borders, or pastes to the skin around the ostomy before putting on the pouch.
- Empty the pouch when it's about a third full.
- Change the pouch before there's a leak, if possible.
- Ask your enterostomal therapy (ET) 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.

## **What caregivers can do**

### **Tracheostomy**

- Learn how to care for the tracheostomy.
- Learn to suction 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. Be sure you know how to clean the humidifier.

## Urostomy and colostomy

- Learn how to care for the ostomy, 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 detailed information on colostomy, ileostomy, urostomy, or related topics, visit [www.cancer.org](http://www.cancer.org) or call us at 1-800-227-2345.

## Swallowing problems

A person may gag, cough, spit, feel pain, or have other problems 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 as you try to swallow
- Weight loss
- Drooling out of the side of mouth or the sense you have too much saliva (spit)
- 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 as if 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 cream-based soups, pudding, 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 or liquids with added thickeners), because they're easier to swallow than thin liquids.
- Mash or puree foods (such as meats, cereals, and fresh fruits) so that they're as soft as baby food. You might 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. If pain gets worse with cold foods, try food at room temperature.
- Try crushed ice and liquids at meals.
- Frequent small meals and snacks may be easier to manage.
- Crush pills or tablets and mix in juice, applesauce, jelly, or pudding. (Check with your nurse or pharmacist first, because some pills 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 and fizzy soft drinks.
- Avoid hard, dry foods such as crackers, pretzels, nuts, and chips.
- Sit upright to eat and drink, and stay that way for a few minutes after meals.
- If pain is a problem, use a numbing gel or pain reliever, such as viscous lidocaine (by prescription) or ask about taking pain medicine before eating. (See the section called "Mouth sores.")
- Ask about seeing a speech-language pathologist 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.
- Sauces and gravies make meats easier to swallow.

## Call the cancer team 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 of 100.5° F or higher 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. There may be enough to soak your clothes. Such sweating is common when a fever breaks. You may notice that you sweat a lot a short time after shaking chills. (See the section called “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’s no fever

### What the patient can do

- Take medicine to reduce fever, such as acetaminophen (Tylenol), if you’ve been told to do so.
- Dress in 2 layers of clothing. The layer on the inside will act as a wick to pull moisture up and away from the skin.
- Change wet clothes as soon as you can.
- Keep your bed linens dry.
- If you’re sweating a lot, bathe at least once a day to soothe your skin and for good hygiene.

### What caregivers can do

- Help the patient keep clothes and bed linens dry.
- Check the patient’s temperature by mouth a few times a day and in the evening.
- Offer extra liquids to replace the fluid that’s lost through sweat.

- Offer to help the patient with a tub bath or shower if needed.

### **Call the cancer team if the patient:**

- Becomes dehydrated from frequent soaking sweats (See the section called “Fluids (lack of) 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. This can be caused by retaining salt and water due to medicines or heart, liver, or kidney failure. It can sometimes be due to poor nutrition, pelvic tumors, or a blockage in the veins or lymph system. Fluid can also build up in the belly. It can make the belly hard and swollen.

### **What to look for**

- Feet and lower legs get larger (swell), usually when you sit in a chair, stand, or walk
- Rings feel too tight for fingers
- Hands feel tight when making a fist
- Large, puffy, hard, 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 heartbeat is fast or irregular)

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

- Limit your salt intake. Avoid using salt in cooking, and don’t eat foods that are very high in sodium (check food labels). Talk with your cancer team about this.
- Eat as well as you can. (See the section called “Appetite, poor.”)
- Take medicines as prescribed.
- If your feet are swollen, rest in bed with them up on 2 pillows.
- When sitting up in a chair, keep your feet raised by sitting in a recliner or by placing your feet on a footstool 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.
- Learn to read food labels and talk with the cancer team about how to keep sodium intake down.
- Don't add salt, soy sauce, or monosodium glutamate when cooking or preparing food.
- Weigh the patient every 1 to 2 days on the same scale, at the same time of day. Keep a list of weights and dates.

### **Call the cancer team if the patient:**

- Can't eat for a day or more
- Hasn't urinated (peed), or has passed very little urine for a day or more
- Has only one arm or leg that swells up
- Can press a finger into a swollen area and the dent remains after the finger is removed
- Has swelling that spreads up legs or arms
- Develops a hard, puffy, or blown-up belly
- Notices that a 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 is sometimes given at home rather than in the hospital or clinic. Pills, intravenous (or IV) chemo, IV antibiotics, shots given under the skin, (called subcutaneous injections and also known as *sub-Q injections*), shots given into a muscle, (intramuscular injections, also called *IM injections*), and other treatments are some of those that can be given at home. Ask your cancer team if this is an option for you.

It's important to take medicines as prescribed and watch for side effects. Sometimes a home care nurse or IV therapy (infusion) nurse will come to your home to give you medicines. Or they might teach you and your caregiver how to give home treatments.

In some cases, home treatments can't be done due to problems with health insurance. Still, patients who can't make frequent visits to the office or clinic might be able to get some kinds of home care. Call your health insurance company to find out more.

## 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 you take pills only once a day, you might want to try taking them just before bedtime to avoid side effects, such as nausea. Check with your cancer team about the best time and way to take each medicine.
- Ask your cancer team about any side effects you may have and ways to control them. (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 cancer team or pharmacist before you cut or crush your pills. Some 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 more about caring for the IV site.

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

- Wash your hands well with soap and water before starting.
- Give shots as instructed by your cancer team.
- Check to be sure that the dosage in the syringe is correct.
- 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, 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 of 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 not to 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 cancer team's office numbers (including emergency numbers) handy.
- If you have a home health nurse who helps with injections, keep their phone number nearby in case you have problems or questions.

## Call the cancer team if the patient:

- Is about to need a prescription refill
- Spills or loses medicine, or vomits a dose
- Learns that any person, other than themselves, has taken their medicine
- Misses a dose
- Has redness, warmth, swelling, drainage, or pain at any injection site
- Has a fever of 100.5° F or higher when taken by mouth
- Has uncomfortable side effects, such as nausea, vomiting, diarrhea, or pain

- Can't give themselves 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 taking any medicine. If this happens, call emergency medical services (911) before calling the cancer team.

## 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 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 have a port (like a small drum) permanently placed in the chest or arm. Special needles are then put into the port to put medicines into it. Some patients have long-term tubes (catheters) that require no needles.

Some medicines are injected into the port or catheter. Other medicines and fluids are given slowly (infused) over minutes or hours. 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 a special pump.

**Tube feedings** give liquid food through a tube placed in the stomach or the small intestine. The tube may go into the stomach through the nose or be put through the skin of the belly and into the stomach.

**Oxygen** can be given through masks or tubes placed just under the nose (called a *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) to avoid putting germs into the blood and causing infections. IV equipment is used only once. It must be handled very carefully. After it's used, it's thrown out and the next time new, sterile equipment is used fresh out of the package.

**Tube feedings and oxygen tubes** are kept clean, but don't have to be sterile. Tube feeding or oxygen equipment can be re-used as long as it's 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. 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 can't, other plans will be made for you to get treatment.

# What the patient can do

## IVs

- Focus on only 1 set of tubing at a time. If you get frustrated, take a deep breath and start again.
- Color code each set of lines with colored tape. For example, red for IV lines, yellow for tube feedings, etc. You might want to use blue tape on oxygen tubes to keep them clearly separate from the IV lines. Keep a record of what each color means, marked in big letters on a nearby wall or headboard.
- 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 cancer team or home health nurse 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, and change it if it gets wet.
  - Watch for redness, swelling, pain, and tenderness at the IV site.
  - Use a calendar to record when you change caps and dressings and to note things like delivery dates and daily weights. Your cancer team will tell you what things you need to keep track of.
  - Call us at 1-800-227-2345 or go to our website at [www.cancer.org](http://www.cancer.org) to learn more about these permanent IV sites, which are often called central venous catheters.
- Keep the IV site clean and dry.
- Avoid the temptation to speed up your IV medicines or fluids. Many 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, check the IV site, and tell your cancer team or home health nurse what you found.
- If the IV comes out or the site starts to bleed, call your cancer team or home health nurse right away.
- Don’t do things that may pull out the IV or rub on the dressing.

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

- Your home care nurse will teach you exactly how to begin and end each infusion.
- If you find that you’re having trouble sleeping because you need to go to the bathroom often, TPN may be infused during the day or early evening.
- Infuse TPN in a room near a bathroom so that you don’t 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, dry 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 nurse. Keep the container out of the reach of children, pets, and others. Your home health nurse will take it when it’s full.
- Always check the expiration date on all your supplies.

### **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 skin on the belly, are for long-term use.
- Give tube feedings at room temperature. Most don’t need to be refrigerated.

- Check the placement of NG tubes and give tube feedings as instructed.
- Cap off the tube as instructed.
- Rinse tubes and bag with water after the feeding is completed.
- 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) to the nostrils if an NG tube is in place.
- Change the tape at the NG tube every other day. Be sure the nostril and skin around the nose 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 but don't use it. Call your cancer team 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 on hand at all times. Even if you use an oxygen machine (concentrator), you'll need a small tank when you leave the house and during power failures.
- If you use a tank, be sure it's attached to a stable cart so it won't fall or roll.
- Don't 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 might need to do these tasks when the patient can't.

- Help the patient. At first, you'll 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 cancer team 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
- Is bleeding from the IV or access site
- Can't flush or use their 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 they 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 treatment side effects. It's important to move and exercise as much as possible to help prevent new problems. Other problems caused by being less active may include poor or no appetite, constipation, skin sores, problems with breathing, stiff joints, worsening fatigue, and mental changes.

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

- Do active or passive range-of-motion exercises as instructed. (See the section called "Exercise.")
- Take pain medicines as prescribed.
- Drink as much liquid as you're allowed.

- 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 resting.
- Wear non-skid shoes (not slippers or clogs that slide off easily) when walking or standing.
- Use any brace, cane, walker, or other support prescribed for you.
- Take short walks if you can. Even if you are bedridden, try to sit up in a chair for meals and get up to use 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 their left arm around you, and put their 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 apart for a firm base and good balance.
- Always lock the wheels on the bed or wheelchair when getting in or out of it.
- Always pull the patient toward you when turning them in bed.
- Clear the floor so that you can help the person to the chair or bathroom without tripping over anything 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 cancer team 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 cancer treatment are common. There are a number of causes for weight loss including:

- Eating less due to nausea or poor appetite
- Diarrhea
- Vomiting
- Dehydration (not taking in enough fluid to make up for fluid that's lost)

Causes for weight gain include:

- Less activity
- Eating more
- Retaining water
- Certain medicines

Quick weight loss is often a sign of dehydration, which can be serious. Weight changes of more than 5 pounds in a week should be reported to your cancer team. A decrease in weight over time may affect the patient's ability to function, and make them weak and unable to perform daily activities. 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 every few days.

## 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**

- See the section called “Fluids (lack of) and dehydration.” Be sure to drink enough water and other liquids.
- Drink extra high-protein and high-calorie fluids between meals.
- Eat high-protein foods. You may also try liquid food supplements.
- Ask about meeting with a dietitian.

### **If you have gained weight**

- Ask if you need to limit fluid if your ankles are swollen.
- Limit your salt intake.
- Limit high-calorie foods.
- Ask about 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. A good time is in the morning before eating or drinking.
- Talk to the cancer team if the patient’s weight loss or weight gain concerns you.
- Watch the patient for other symptoms.

### **Call the cancer team 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

If you are caring for a loved one who has advanced cancer, you may be there as they near death and even when they die. Even as you go through the pain of losing someone close to you, there are many things you can do to make the person more comfortable.

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's a chance for many families and friends to express their love and appreciation for the patient and for each other.

It's 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 cancer team 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 *Hospice Care* and *Nearing the End of Life*. You can also visit [www.cancer.org](http://www.cancer.org) for more information.

## What to look for

- Profound weakness – usually the patient can't get out of bed and has trouble moving around in bed
- Patient needs help with nearly everything they do
- 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, and they may be hard to rouse or wake
- Short attention span; patient may not be able to focus on what's happening
- Confusion about time, place, or people
- Trouble swallowing pills and medicines
- Limited ability to cooperate with caregiver

## Possible changes in body function

- Weakness – trouble moving around in bed, and may become unable to get out of bed
- Can't 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 the patient turn and change positions every 1 to 2 hours.
- Avoid sudden noises or movements to lessen the startle reflex.
- Speak in a calm, quiet voice to reduce the chance of startling the patient.
- If the patient has trouble swallowing pain medicines, ask the cancer team 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
- The patient is restless and may pick at 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 they are mentally clear before going back into semi-consciousness

## **What caregivers can do**

- Plan your times with the patient when they are most alert or during the night when your presence may be comforting.
- When talking with the patient, remind them who you are and what day and time it is.
- Keep giving pain medicines up to the end of life. If the patient is very restless, try to find out if they are having pain. If it appears so, give pain medicines as prescribed, or check with the cancer team 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, and has less need for food and drink.
- The mouth may dry out. (See “Possible changes in secretions” below.)
- The patient may no longer need some of their 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 cancer team 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.)
- Mucus may thicken due to a lower fluid intake and build up because the patient cannot cough.

## **What caregivers can do**

- Help make the mucus thinner 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 mucus.
- Change the patient's position. Turning the patient to the side may help mucus 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 health nurse.

## **Possible changes in circulation and temperature**

- Arms and legs may feel cool to the touch as blood circulation slows down.
- Skin of arms, legs, hands, and feet may darken in color and look blue or mottled (blotchy).
- Other parts 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 harder to hear.

## **What caregivers can do**

- Keep the patient warm with blankets or light bed coverings.
- Don't use electric blankets, heating pads, or other heating devices.

## **Possible changes in senses and perception**

- Vision may become blurry or dim.
- They may not hear quite as well, 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 can't hear you.

- Keep talking with and touching the patient to let them know you're there. Your words of affection and support are likely to be heard 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

- Turn the patient on their 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 (pee), which may be darker in color
- When death is near, there may be loss of control of urine and stool (poop).

## What caregivers can do

- Put soft waterproof pads under the patient's bottom to make it easier to clean up.
- If the patient has a catheter to collect urine, 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's OK to sit with your loved one for a while. There's 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 you have a hospice or home care agency, call them first. If you've made funeral arrangements, calling the funeral director and cancer team might be all you have to do.
- If the patient dies at home and is not under hospice care, caregivers must call the proper people. Laws about who must be called and how the body should be moved differ from one community to another. Your cancer team can help you get this information.

**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 them 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**

Here is more information you might find helpful. You can order free copies by calling our toll-free number, 1-800-227-2345, or visit [www.cancer.org](http://www.cancer.org) to read them on our website.

### **Coping with cancer**

Coping With Cancer in Everyday Life (also in Spanish)

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

Anxiety, Fear, and Depression (also in Spanish)

Distress in People With Cancer

Home Care Agencies (also in Spanish)

Fertility and Women With Cancer

Fertility and Men With Cancer

## **Cancer treatments**

A Guide to Chemotherapy (also in Spanish)

A Guide to Radiation Therapy (also in Spanish)

A Guide to Cancer Surgery (also in Spanish)

Oral Chemotherapy: What You Need to Know

Stem Cell Transplant (Peripheral Blood, Bone Marrow, and Cord Blood Transplants)  
(also in Spanish)

Understanding Your Lab Test Results

## **Side effects of cancer and cancer treatment**

Guide to Controlling Cancer Pain (also in Spanish)

Anemia in People With Cancer

Nausea and Vomiting

Fatigue in People With Cancer

Sexuality for the Man With Cancer (also in Spanish)

Sexuality for the Woman With Cancer (also in Spanish)

## **Work, insurance, and financial issues**

Family and Medical Leave Act (also in Spanish)

## **Helping children with cancer in the family**

Helping Children When A Family Member Has Cancer: Dealing With Treatment (also 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

## **Talking and listening**

Listen With Your Heart (also in Spanish)

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



Talking With Your Doctor (also in Spanish)

## **Advanced cancer and end of life**

Advanced Cancer (also in Spanish)

Bone Metastasis (also in Spanish)

Nearing the End of Life (also in Spanish)

Advance Directives

Hospice Care (also in Spanish)

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

Helping Children When A Family Member Has Cancer: When A Child Has Lost A Parent

## **Books**

Your American Cancer Society also has books that you might find helpful. Call us at 1-800-227-2345 or visit our online bookstore at [www.cancer.org/bookstore](http://www.cancer.org/bookstore) to find out about costs or to place an order.

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