

EDUCATIONAL MANUAL

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MISSOURI CANCER CARE, P.C.

PHILOSOPHY

WE ARE IN THE PEOPLE BUSINESS AND HAVE AN UNCOMPROMISING COMMITMENT TO PLACE OUR PATIENTS FIRST IN OUR PRACTICE.

OUR GOAL IS TO PROVIDE SERVICE OF THE HIGHEST QUALITY FOR OUR PATIENTS IN A WARM AND CARING ENVIRONMENT.

PATIENTS BRING US THEIR WANTS, IT IS OUR DUTY TO HANDLE THEM WITH CARE AND COMPASSION AT ALL TIMES. THEY DO US A FAVOR BY LETTING US SERVE THEM. THEY DESERVE COURTEOUS, ATTENTIVE TREATMENT BECAUSE THEY ARE FLESH AND BLOOD HUMAN BEINGS WITH FEELINGS AND EMOTIONS LIKE OUR OWN. THEY ARE THE MOST IMPORTANT PEOPLE IN OUR PROFESSION AND OUR PRACTICE.

A RESOURCE FOR YOU AND YOUR LOVED ONES

We realize how frightening a diagnosis of cancer can be for a patient and their loved ones. One of our goals is to provide you with the information and support you need to manage the physical and emotional disturbances to your normal life.

The first important resource for you and your family is education -- education about your diagnosis and treatment. This notebook is being provided for your convenience in organizing the information which we give you. The notebook provides basic information about the diagnosis of cancer, various treatments, side effects of treatment, and community resources available to you. In addition, special information about the drugs the doctor has ordered to treat your cancer are provided. Definitions for medical terms which may be new to you are also given.

This notebook is not intended to be a complete resource. Throughout your treatment process you will receive more detailed information about your specific cancer and treatment. Use this notebook to organize all information given to you.

We hope this information will help you in the days ahead. Your well-being is important to us. Please let us know if you need more detailed information or you need clarification of any information contained in this notebook.

LIVING WITH CANCER

A diagnosis of cancer creates a physical, emotional, social and spiritual crisis for patients and their loved ones. Life-style, goals, plans and dreams are disrupted. You may find at first that you are in shock, unable to accept the diagnosis. You may feel overwhelmed with new information and confused by unfamiliar medical terms and procedures. Rational thinking and good personal decision making become very difficult as you try to adjust to this new and frightening situation. You may feel this is happening to someone else and you are just an onlooker, unable to change the course of events. You may even deny the problem or its implications for your life and your future.

Gradually, your ability to think clearly and to participate in treatment decisions will improve. Panic subsides but periods of fear, anger, and anxiety are normal as you go through treatment and face unfamiliar and stressful situations. At times you and your family may feel that your lives are out of control. But, crisis situations also bring opportunity for growth, closeness, and new appreciation of life and relationships. Many people find it helps to focus on living for today -- here and now -- rather than on long term, future plans. Short term goals and giving yourself regular rewards may help you get through difficult times. Sharing thoughts and feelings with others can help you get the emotional support you need.

Many patients agree that their ability to cope through the cancer experience came from the care and concerns of others. Isolating yourself from others increases depression and feelings of helplessness. You are not in this situation alone; your family and friends are here for you and they need to help you in order to help themselves. During this time, people will want to reach out to you and offer their services. It is important for you to accept these acts of kindness, as it allows you to stay in touch with others and makes them feel helpful. So many times, those that care about you most are also feeling isolated and helpless. Encourage family members to keep involved with their own friends. Coping with cancer is made easier by the energy, caring, and sharing of others. Friends, family, church, and community support are all very valuable means of strength.

We are committed to helping you deal with every aspect of your cancer experience. We know that some patients and families may experience a more difficult time coping with the stresses of cancer and cancer treatment, and support from others is not enough. In this event, your doctor can refer you to professionals that can offer individual and family counseling.

GENERAL INFORMATION ON CANCER

What is cancer?

Cancer is a group of more than 100 different diseases. Cancer occurs when cells become abnormal and keep dividing and forming more cells without control or order.

All organs of the body are made up of cells. Normally, cells divide to produce more cells only when the body needs them. In other words, the body controls the rate of production or replacement of cells. If cells keep dividing when they are not needed, a mass of tissue forms. This mass of extra tissue, called a growth or tumor, can be benign or malignant.

Benign Tumors are not cancer. They can usually be removed and, in most cases, they do not come back. Most important, cells from benign tumors do not spread to other parts of the body. Benign tumors are rarely a threat to life.

Malignant Tumors are cancer. Cancer cells can invade and damage nearby normal tissues and organs. Also, cancer cells can break away from a malignant tumor and enter the blood stream or the lymphatic system. This is how cancer spreads from the original (primary) tumor to form new tumors in other parts of the body. The spread of cancer is called metastasis.

Most cancers are named for the type of cell or the organ in which they began. When cancer spreads, the new tumor has the same kind of abnormal cells and the same name as the primary tumor. For example, if lung cancer spreads to the liver, the cancer cells in the liver are actually lung cancer cells. The resulting disease is called metastatic lung cancer, not liver cancer.

What causes cancer?

Our current understanding of the causes of cancer is not complete. It is clear that cancer is not caused by an injury such as a bump or a bruise. And, although being infected with certain viruses may increase the risk to get certain types of cancer, cancer is not contagious; no one can "catch" cancer from another person.

Cancer develops gradually as a result of a complex mix of factors related to environment, life style, and heredity. Scientists have identified many risk factors that increase the chance of getting cancer. They estimate that about 80% of all cancers are related to the use of tobacco products, to what we eat and drink, or, to a lesser extent, to exposure to radiation or cancer causing agents (carcinogens) in the environment and workplace. Some people are more sensitive than others to factors that can cause cancer.

Many risks can be avoided. Others, such as inherited risk factors, are unavoidable. It is helpful to be aware of them, but it is also important to keep in mind that not everyone with a particular risk factor for cancer actually gets the disease; in fact, most don't.

How is cancer diagnosed?

After a physical exam, the doctor will order various tests and exams. These may include imaging procedures such as a CT and MRI, which produce pictures of areas inside the body; endoscopy, which allows the doctor to look directly inside certain organs; and laboratory tests. In most cases, the doctor also orders a biopsy, a surgical procedure which removes a piece of suspicious tissue. A pathologist examines the tissue under a microscope to check for cancer cells. If cancer cells are found during the pathological examination, the diagnosis of cancer is confirmed.

CANCER TREATMENTS

How is cancer treated?

Cancer is treated with surgery, radiation, chemotherapy, hormones, or biologicals. Many types of cancer will be treated with a combination of two or more types of therapy. Patients with cancer are often treated by a team of specialists which are coordinated by the medical oncologist.

Surgical Treatment

Surgical treatment is recommended for many types of cancer. Often, chemotherapy, radiation, or other therapy will precede or follow surgery. Surgery is a local treatment that removes the tumor and any nearby tissue that may contain cancer cells. Sometimes, healthy tissue may be removed to insure that all the cancer cells have been removed.

Cancer cells spread by the blood stream or the lymphatic system. The lymphatic system carries lymph fluid throughout the body and is important in fighting infection and removing unwanted particles from the body. Unfortunately, it can also carry cancer cells. Therefore, the surgeon may remove lymph nodes that are near the tumor to see if they contain cancer cells. The number of affected nodes (those containing cancer cells) are used to "stage" the cancer. Staging is a way to classify the extent of cancers and the prognosis. Different stages require different treatments.

Surgery can cause some side effects depending on the type of operation, your general health, and other factors. Pain or soreness at the site of the operation is common but will subside in a few days. Since some nerves were cut during the surgery, you may feel numbness or tingling around the incision site, too. These problems usually go away within a few weeks, although some numbness may be permanent. You may feel tired or weak for a while. Remember, it takes time to recover from any operation and that the amount of time needed will differ from patient to patient.

Radiation Therapy:

Radiation therapy uses high energy x-rays to damage cells so they are unable to grow or multiply. Like surgery, it is a local treatment and affects only the cells in the treatment area. Radiation therapy may be used alone to destroy those tumors which cannot be surgically removed. It may be used before surgery to shrink the tumor or after surgery to destroy any cancer cells that may remain in the area. Radiation therapy may also be used as a palliative measure (treating the symptoms but not curing the cancer) to manage pain or other local complications associated with tumor growth. There are two types of radiation therapy: external radiation and radiation implants.

External radiation uses radiation from a machine and is usually given on an outpatient basis 5 days a week for several weeks. Patients are not radioactive during or after treatment.

Internal radiation (also called brachytherapy) uses a small container of radioactive material (called an implant) which is placed at or near the tumor. The patient is usually admitted for a few days. The implant may be permanent or temporary. Because the level of radiation is highest during the hospital stay, patients may not be allowed visitors or may only have them for a short time. Once an implant is removed, there is no radioactivity in the body. The amount of radioactivity of a permanent implant goes down to a safe level before the patient leaves the hospital.

Side effects of radiation therapy depend on the treatment dose and the part of the body which is treated. The most common include: tiredness, skin rash or redness, and loss of appetite. It may also decrease the number of white blood cells which help fight infection. Although the side effects are temporary, the doctor can usually

control them if they become too unpleasant.

Patients who have had radiation should continue special care used during the treatment, at least for a short while. Continue to be gentle with skin in the treatment area until all signs of irritation are gone. Do not scrub off the markings, they will fade and wear away. Tiredness may continue while healthy tissue is rebuilding. Take naps and get more sleep as needed. Wait to resume full activities until your strength returns.

Radiation therapy continues to work for 4-6 weeks after the last treatment. Further x-rays to determine effectiveness of the treatment will be postponed until all therapeutic radiation activity has stopped.

CHEMOTHERAPY & BLOOD

CONCEPTS OF CHEMOTHERAPY AND ITS EFFECTS

Chemotherapy is the use of drugs to control or destroy cancer cells. Cancer cells grow in a rapid and disorganized way, unlike normal cells. Chemotherapy works by interfering with the growth or reproduction of cancer cells. Chemotherapy is usually given intravenously but it may be given orally in some situations. Chemotherapy travels throughout the entire body.

Our bodies have normal cells that grow rapidly in the bone marrow, gastrointestinal tract and hair follicles. Because chemotherapy cannot distinguish between rapidly growing cancer cells and rapidly growing normal cells, the non-cancerous cells can be affected, thus causing side-effects. Not everyone experiences side-effects. If side-effects from your treatment do occur, they are usually only temporary and can often be controlled. Side-effects often depend on the drug dosage, sometimes the dosage will need to be adjusted, depending on each individual circumstance. Medication may ease or control side-effects while you are being treated with chemotherapy and/or radiation therapy. Let us know when you are experiencing side-effects, most side-effects can be controlled.

Chemotherapy may affect the action of many drugs. Consult your doctor before taking any medication while on chemotherapy. It is best to avoid any medications (including over-the-counter drugs) which contain aspirin while on chemotherapy. Please bring all medications that you take for this or any other condition when you come for your doctor visit. This includes over-the-counter or non-prescription drugs and vitamins. Check with your doctor before taking any medications.

CHEMOTHERAPY --CARE AT HOME

Because you have received chemotherapy as a method of treating your cancer, there are some things you must remember when you go home. Not all patients will experience these side effects.

WHEN TO CALL THE DOCTOR:

1. Temperature 100.5 or greater.
2. Shaking chills with or without a fever.
3. Unusual bleeding such as a sudden nosebleed or excessive bleeding.
4. Vomiting or diarrhea that lasts longer than 24 hours without relief.
5. Painful sores that develop in your mouth, oral tenderness that interferes with eating.
6. Severe lightheadedness or dizziness.
7. Severe pain or discomfort that does not go away with usual pain pills.
8. Severe cough or shortness of breath.

THE PHONE # TO CALL FOR WENTZVILLE PATIENTS IS 332-5875.

THE PHONE # TO CALL FOR ST. CHARLES PATIENTS IS
947-4007.

THE PHONE # TO CALL FOR ST. PETERS PATIENTS IS
498-4440.

These numbers are answered by an answering service 24 hours a day/7 days a week.

CHEMOTHERAPY & BLOOD

EFFECTS ON THE BONE MARROW AND BLOOD:

The bone marrow is where your blood cells are made. The bone marrow makes all kinds of blood cells: red blood cells, white blood cells, and platelets. These cells divide rapidly. Chemotherapy may decrease their number.

The red blood cells give you energy. If they decrease in number, you may feel weak or fatigued. White blood cells fight infection. If there is a decrease in these cells, you may be more susceptible to infection. Platelets help the blood to clot, so during chemotherapy you may bruise more easily or find that cuts take longer to stop bleeding.

Your doctor will monitor your blood count with regular tests. Your blood count should return to normal within a few weeks after your chemotherapy treatment. You should continue your normal exercise and activities. Allow for additional rest periods if you tire more easily.

White blood cells (WBC's) are your blood cells that fight infection. Some chemotherapy treatments will cause a low WBC. The specific cell of importance is the neutrophil. Its main function is to protect the body from infection. Neutropenia means that your white blood cells are low. This typically occurs 1 to 2 weeks after chemo but can vary based upon the chemotherapy regimen and patient. If your count is low when treatment is scheduled, the treatment may be held or postponed until the WBC returns to a safe level, or dosages may be adjusted.

Neutrophil counts of less than 500 puts patients at the highest risk for infection.

Neutrophil counts of less than 1000 puts the patient at risk.

You can stay home with neutropenia (versus hospitalization) especially if the chemotherapy treatment is given in the office or in the hospital outpatient department. Sometimes, the doctor will give you a drug to stimulate the production of neutrophils (Neupogen or Leukine). These are specific hormones or growth factors for bone marrow.

CHEMOTHERAPY & BLOOD

NEUTROPENIC INSTRUCTIONS

While at home with neutropenia you should:

Call the office IMMEDIATELY for a temperature of 100.5 or above (even at night or on the weekend). 636-947-4007, 636-332-5875, 636-498-4440.

Call the office IMMEDIATELY for shaking chills, with or without a fever.

If your WBC is very low and your doctor or nurse tells you; then follow these neutropenia precautions until your WBCs come back up.

- Check temperature three times daily, or if you feel like you have a fever.
- Do not take Acetaminophen (Tylenol) unless instructed to do so by your physician.
- Do not take aspirin or any products containing aspirin.
- Wash hands frequently, especially after eating and using the bathroom.
- Buy a new toothbrush; do not have any dental work done without consulting your doctor or nurse.
- Use a fresh, clean cup each time you drink water or other beverages. Do not drink from cans or bottles, or after anyone else.
- Carry out mouth care at least 4 times daily.
- Avoid contact with anyone who is sick or has a cold.
- Wash your body thoroughly each day.
- Avoid eating fresh, unpeeled raw fruits, vegetables and salads, uncooked eggs, raw fish or unpasteurized milk.
- Keep active with exercise or walking.
- Wear shoes at all times, avoid manicures and pedicures.
- Wear gloves when gardening.
- Do not clean bird cages, cat litter boxes, or fish tanks.
- Use water-based lubricants (K-Y Jelly, Astroglide) to reduce friction during intercourse - avoid anal intercourse - women should urinate before and after intercourse.
- Avoid hot tubs, Jacuzzis; swim only in pools where the chlorine content is carefully monitored (needs to be adequately high to eliminate bacteria).
- Limit exposure to fresh cut flowers and houseplants.
- Avoid sources of stagnant water (flower vases, dentures cups, humidifiers); water in these containers should be changed daily by someone else.
- For cuts and scrapes, clean the area immediately with soap and warm water, and apply a bandage - check the site daily for signs of infection.

- Use an electric shaver instead of a razor blade.
- Do not use enemas, rectal thermometers, rectal or vaginal suppositories, tampons or douches.
- Get enough rest and avoid stress as much as possible.
- No dental procedures.

CHEMOTHERAPY & BLOOD

THROMBOCYTOPENIA INSTRUCTIONS

Thrombocytopenia means that your platelet count is low. The chief function of platelets is to protect the body from bleeding. Platelets are the clotting factors of your blood. If your count is low, you are at greater risk for spontaneously bleeding and bruising. If severely low, you may need a platelet transfusion.

Platelet counts of greater than 150,000 are considered normal.

Platelet counts of 50,000 to 150,000 are usually safe unless surgery or other invasive procedures are needed.

Platelet counts of less than 20,000 may be treated with a platelet transfusion.

While at home with thrombocytopenia you should:

- Call office for sudden, new onset, severe, persistent pain -- especially new headache, acute abdominal pain.
- Call office with any observation of blood in urine, stool, vomiting, or sputum.
- Do not lift any heavy objects.
- Avoid clothes with tight elastic.
- Call with any new onset of blurred vision, confusion or drowsiness.
- Observe for bleeding from gums or nose; call for any nosebleed that will not stop, blow nose gently if you have to.
- Wear shoes at all times to prevent injury.
- Do not use enemas, rectal thermometers, rectal or vaginal suppositories, tampons or douches.
- Use water-based lubricant (K-Y Jelly, Astroglide) to reduce friction during intercourse; avoid anal intercourse.
- Follow daily bowel program to prevent constipation/rectal bleeding.
- Observe total body for bruising or pinpoint purplish spots on skin. Be sure to check chest and back; call the office for increased or severe bruising.
- Use an electric shaver, not a razor for shaving.
- Use soft bristly brush or toothette for oral care; do not use dental floss.
- Do not participate in contact sports -- football, basketball, soccer or wrestling, karate, etc.
- Do not take aspirin or aspirin containing products without checking with your doctor.
- Do not take any new medication without checking with your doctor.
- Use gloves when doing yard work -- avoid use of sharp knives and other tools.
- If you injure yourself and bleed, apply pressure to the area until bleeding stops.
- Contact our office before having any dental work done.
- Call your doctor for any bleeding that is unusual or doesn't stop; or an increase in menstrual flow.

Anemia Instructions

Anemia means that your red blood cells (RBC's) are low. RBC's carry oxygen to the tissues of the body. You may feel tired, short of breath, weak and may require a transfusion or treatment with drugs to stimulate the production of RBC's. It is important to conserve your energy until your RBC count returns to normal, or you receive a transfusion.

General guidelines when anemic:

- Avoid all strenuous activity.
- Adjust activity according to how you feel.
- Plan frequent rest periods during your day.
- Try to do some form of light exercise (like walking) every day.
- Change positions slowly to avoid dizziness/lightheadedness.
- Eat a well-balanced diet to promote a feeling of well-being.
- Immediately notify your physician for any change in your symptoms.

Your RBC count is measured in two ways. The hemoglobin, which is the amount of oxygen carrying protein in the blood and the hematocrit which is the percentage of red cells in the blood.

Safe RBC count	May Need Transfusion	Often Needs Transfusion
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Hemoglobin >10 is safe	Hemoglobin 8-10	Hemoglobin < 8
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Hematocrit >30 is safe	Hematocrit 25-30	Hematocrit < 24
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Erythropoietin (Epogen or Procrit), which is another bone marrow hormone or growth factor given to stimulate the production of RBC's, may sometimes be given if hemoglobin is low to improve anemia without a transfusion. However, this may take several doses to notice an improvement and may not work in everyone.

SPECIFIC SYMPTOM MANAGEMENT

MANAGING HAIR LOSS

Many chemotherapy drugs can cause hair loss (alopecia), others may cause thinning, and some will not affect your hair. Often, patients perceive hair loss as an outward sign of illness which everyone can see. This can be emotionally, socially and psychologically disturbing. To help deal with any hair loss, we suggest you:

- Comb hair gently or brush with a soft brush.
- Wash hair with a mild pH balanced shampoo.
- Use an electric razor to shave beards, mustaches, underarms and legs.
- Style hair in a short, easy to manage style.
- Purchase a wig prior to losing your hair to have your natural color and style matched.
- We have several places that we recommend for wigs, ask one of the nurses.
- If you have partial or complete hair loss be sure to use sunscreen, wear a hat or scarf to protect your scalp from sunburn.
- Free wigs and turbans are available at the Cancer Information Center at St. Joseph's Health Center in St. Charles. Free wigs are also available at the American Cancer Society on Boonslick in St. Charles.

Note: A feeling of anger and depression is often associated with hair loss. This is a common reaction, talking to someone about what is happening may help.

Hair loss associated with chemotherapy is temporary and your hair will begin to grow back about one month after your last chemotherapy treatment. Sometimes your hair will grow back a different color and/or texture.

SPECIFIC SYMPTOM MANAGEMENT

Chemotherapy and its effects on the Gastrointestinal System:

The cells that line your mouth, stomach and intestines reproduce to make new lining every 24 to 48 hours. Chemotherapy may upset this normal process. The mouth may develop sores, called stomatitis or mucositis. These sores usually begin with a drying or reddening of the lining of the mouth. Avoid using commercial mouth washes as they contain alcohol which causes more drying and irritation. Use a soft toothbrush or sponge toothette for cleaning. Your doctor may prescribe a mouth wash to rinse or gargle with before and after meals.

If your stomach lining becomes irritated, you may develop nausea and/or vomiting. If the lining of your intestines becomes irritated, there may be a change in your bowel function (diarrhea or constipation). Your doctor will prescribe medication to control these side effects.

SPECIFIC SYMPTOM MANAGEMENT

MANAGING NAUSEA AND VOMITING

Many chemotherapy drugs may cause nausea and vomiting. You will likely receive medications before chemotherapy and pills to take at home to prevent this. Additional measures that may help include:

- Eat smaller meals, more often during the day. Do not force fluid or food when nauseated or vomiting.
- Avoid liquids at mealtimes.
- Avoid sweet or fatty foods -- coffee, bacon, meat, pork, pies or cakes.
- Eat slowly and rest quietly after meals for about an hour. Use relaxation techniques such as listening to music or thinking of pleasant images, watching T.V., or talking to someone.
- Sleep through times of increased nausea, if possible.
- Chew food well.
- Eat small amounts of dry foods such as toast, crackers or pretzels.
- Do not lie flat for at least 2 hours after eating.
- At first try small amounts of cracked ice, water, or soda, then as tolerated drink fluids to replace losses, especially Gatorade or similar sport drink.
- Eat cool foods such as gelatin, popsicles, or custards.
- Eat small, frequent meals of easily digested foods such as soup, toast, rice, boiled or baked potatoes, eggs, and juices.
- Avoid hot foods; odors sometimes cause nausea.
- Perform frequent mouth care to avoid bitter/sour taste in mouth.
- Take your nausea medicine, _____, as ordered by your doctor: _____.
- Notify your nurse or doctor if your nausea medicine does not work.

SPECIFIC SYMPTOM MANAGEMENT

MANAGING MOUTH SORES

Some chemotherapy drugs cause a breakdown in the lining of the mouth and mouth sores develop. If left untreated, the sores can become infected. To help avoid infection if mouth sores develop you should:

- Avoid highly acidic foods such as citrus fruits or juices.
- Avoid highly spicy foods.
- Eat bland, soft, moist foods.
- Eat frequent small meals.
- Avoid cigarettes and alcohol, these are irritating or cause dryness.
- Keep mouth and gums clean. You may use toothettes or cotton swabs rather than a toothbrush to keep your mouth clean.
- Make sure dentures fit properly.
- Avoid commercial mouthwash, toothpicks, dental floss and waterpics.
- Gargle 4 times a day with weak salt water and baking soda solution. To make: 1/4 teaspoon salt and 1/4 teaspoon baking soda in 8 oz water.
- Use artificial saliva, if necessary (e.g., Xero-lube, Salivart - no prescription required).
- Apply lubricant to your lips frequently.
- Drink at least 2 or 3 quarts of liquid a day unless otherwise instructed by your physician/nurse.
- Eat cool foods such as gelatin, popsicles or custards instead of hot foods/beverages.
- Eat foods that have been processed in a blender or drink liquid nutritional supplements especially if swallowing is difficult (Nutritional supplements being Carnation Instant Breakfast Drink, Ensure, Boost, Sustacal, etc.).
- Notify your doctor or nurse about your symptoms.
- If you have dentures/partial plate, remove before oral care - cleanse and store in denture antiseptic solution (e.g. Efferdent), changing solution daily to prevent growth of bacteria.

SPECIFIC SYMPTOM MANAGEMENT

MANAGING DIARRHEA

Some chemotherapy drugs will cause diarrhea. Like vomiting, diarrhea can cause more serious complications if uncontrolled. To help control diarrhea, we suggest you:

Drink a variety of fluids, at least 8 to 10 large glasses of liquids a day to help prevent dehydration.

- water should only be part of the 8 to 10 glasses a day; it does not replace lost minerals.
- drink slowly and drink small quantities often.
- Gatorade or a similar sport drink is a good source of fluids, it replaces lost salt and potassium.
- clear soup or broth, clear juice (except apple)
- soda...let stand until fizz has decreased to prevent more gas or bloating.

Eat small, more frequent meals instead of 3 large meals.

Avoid milk and dairy products until diarrhea subsides.

Avoid alcohol and coffee (and other caffeinated beverages). Also avoid decaffeinated coffee.

Avoid tobacco.

Avoid very hot or very cold beverages.

Avoid foods that cause gas, cramps or stimulate bowel movements such as fresh leafy vegetables, fresh raw fruits and raw vegetables, nuts, spicy foods, corn, beans, or cabbage. Whole grain bread and cereals, bran, fried or greasy food, rich pastries, candy, jellies, strong spices/herbs, popcorn, and chocolate.

Eat foods that are low in fiber, such as: macaroni, bananas, white boiled rice, applesauce or white toast. Add nutmeg to rice or applesauce. Cottage cheeses, baked potato, smooth peanut butter, yogurt, cooked cereals.

When these foods are well tolerated, you can add: chicken (white meat without the skin), scrambled eggs, crackers and white breads, canned or cooked fruits without the skins.

What to do:

If you are having frequent very loose or watery stools a day, if you are having diarrhea during the night or if you are having uncontrollable bowel movements: Start taking Imodium AD (available without a prescription). Take 2 tablets initially, then 1 after each loose bowel movement up to a maximum of 8 tablets in a 24 hour period. If diarrhea does not improve then call your doctor, a prescription medication may need to be added.

SPECIFIC SYMPTOM MANAGEMENT

Constipation, impaction, and bowel obstruction

Constipation, impaction and bowel obstruction are common problems for cancer patients, cancer itself, as well as its treatment, contribute to these conditions.

Constipation is the infrequent passage of small, dry, hard feces with discomfort or pain. While constipation is annoying and uncomfortable, fecal impaction (a collection of dry, hard feces in the colon or rectum) can be life-threatening. Patients with impaction may have circulation, heart or breathing problems instead of gastrointestinal symptoms.

A bowel obstruction can be either a partial or complete blockage of the intestine. Bowel obstructions are classified by the type of obstruction, how it is obstructed, and where it is obstructed. Structural disorders caused by tumors or complications after surgery can affect bowel function, leading to partial or complete obstruction. Patients with colostomies are especially at risk of developing constipation, which can lead to obstruction.

Inactivity, immobility, or physical and social difficulties (e.g., bathrooms unavailable or inconvenient) can make constipation worse. Depression and anxiety caused by cancer treatment or pain can also lead to constipation.

CONSTIPATION: DESCRIPTION AND CAUSES

Common causes of constipation in people with cancer are diet, changed bowel habits, and lack of exercise. Causes of constipation in cancer patients can be cancer-related problems (such as pain), the effects of drugs for cancer treatment, and changes in the body (such as organ failure, inactivity, and depression). Other causes include dehydration and not eating or drinking enough of the right types of food. These factors can occur because of the cancer, its treatment, aging, or declining health.

Constipation may be caused by not getting enough fluids and/or fiber in the diet, or by changed bowel habits, such as ignoring the urge to pass stool or using too many laxatives or enemas. Lack of exercise due to spinal cord injuries or compression, bone fractures, tiredness or weakness, or breathing or heart problems can also lead to constipation. Some medications used to treat cancer, pain, sleeplessness, depression, and other problems may have constipation as a side effects. Vitamins, diuretics, and general anesthesia can also cause constipation.

Certain disorders of the body can lead to constipation, such as bowel problems (irritable colon or diverticulitis), tumors, paralysis, and weak stomach muscles. Lead poisoning, decreased thyroid function, too much calcium, metabolic problems, and antidepressant medication can also lead to constipation. Emphysema and a weak diaphragm (problems breathing) can make having a bowel movement difficult, leading to constipation. Malnutrition and muscle stiffness due to senility and inactivity can also cause constipation.

The environment that a cancer patients lives in can also lead to constipation, such as needing assistance when going to the bathroom, being in a strange or hurried environment, extreme heat leading to dehydration, and changing bathroom habits (e.g., needing to use a bedpan). The colon may be affected by radiation therapy, surgery, or some cancer treatments also causing constipation.

To determine the possible causes of constipation and the possibility of impaction, a doctor will perform a physical examination and may ask the following questions:

- What is normal for you: how often do you have a bowel movement, when, and how much?
- When was your last bowel movement? What was it like (how much, hard, soft, color)? Was there any blood?
- Has your stomach hurt or do you have any cramping, nausea, vomiting, pain, gas, or feeling of fullness near the rectum?

SPECIFIC SYMPTOM MANAGEMENT

SENOKOT-S Tablets Laxative Protocol

Many prescription medications can cause constipation. Bowel function is also affected by activity and diet. For example, regular doses of narcotic pain-relieving medication frequently cause constipation. A medication regimen that also includes use of a laxative is almost always required to avoid constipation

A daily bowel regimen should be followed just as carefully as your doctor's other instructions. The overall goal is to have a bowel movement approximately every few days. Because responses vary, use the guidelines below to find a regimen that works best for you. If at any time the dosage of your pain-relieving medication is changed, you may also need to increase or decrease your daily dosage of laxative. See your doctor for a change in dose.

1. Take 2 Senokot-S tablets at bedtime. (If you do not have a bowel movement in the morning)
2. Take 2 Senokot-S tablets after breakfast. (If you do not have a bowel movement by evening)
3. Take 3 Senokot-S tablets at bedtime. (If you do not have a bowel movement in the morning)
4. Take 3 Senokot-S tablets after breakfast. (If there is no bowel movement within 48 hours after starting the protocol)
5. Add Lactulose (call for a prescription) after breakfast, while continuing to take 3 Senokot-S tablets in the morning and 3 Senokot-S tablets in the evening.

If there is no bowel movement within 24 hours after beginning this protocol, please consult your physician for additional instructions. Once you start having bowel movements, use the 2 steps prior to your last one as your daily laxative protocol. For example, if you achieved a bowel movement after Step 4, use Steps 2 and 3 (that is, 2 Senokot-S tablets in the morning and 3 Senokot-S tablets at bedtime) as your daily regimen.

Remember, constipation is a common side effect of many medications. A daily bowel regimen helps to prevent this potentially troublesome side effect.

If you are unsure about what to do, please call your physician for advice

FATIGUE

Fatigue is a feeling of tiredness that can keep you from doing the things you normally do or want to do. Fatigue is a very common among people receiving cancer treatments. Factors such as cancer itself, low blood counts, nutritional problems and sleep problems contribute to fatigue, but the exact cause is not known.

SIGNS OF FATIGUE:

- You feel weary or exhausted. It may be physical, emotional, and/or mental exhaustion.
- Your body, especially your arms and legs, may feel heavy.
- You have less desire to do normal activities like eating or shopping.
- You may find it hard to concentrate or think clearly.

WHAT YOU CAN DO:

REST

Rest and sleep are important, but don't overdo it. Too much rest can decrease your energy level. In other words, the more you rest the more tired you will feel. If you have trouble sleeping, talk to your doctor or nurse.

ACTIVITY

Stay as active as you can. Regular exercise like walking several times each week may help.

NUTRITION

Drink plenty of liquids. Eat as well as you can and eat nutritious foods.

ENERGY CONSERVATION

You can do more by spreading your activities throughout the day. Take rest breaks between activities. Rest breaks save energy for the things you want to do. Let others help you with meals, housework or errands. Do not force yourself to do more than you can manage. Avoid extremes of temperature. Eliminate smoke or noxious smells. Avoid long, hot showers or baths.

ENERGY RESTORATION

Do activities that you enjoy and make you feel good. Many people enjoy nature activities such as bird watching or gardening. Try listening to music or visiting with friends and family or looking at pleasant pictures.

TALK TO YOUR ONCOLOGY NURSE OR DOCTOR

- If you have been too tired to get out of bed for the past 24 hours.
- If you feel confused or cannot think clearly.
- If your fatigue becomes worse.

WHAT IS CANCER TREATMENT-RELATED FATIGUE?

A feeling of tiredness, often more severe than the tiredness healthy people experience. It is seen in people who have surgery, radiation treatments, chemotherapy or other forms of cancer treatment. The cause is not fully known.

HOW DO PEOPLE DESCRIBE CANCER TREATMENT-RELATED FATIGUE:

Individuals with cancer have described fatigue as weakness; exhaustion; tiredness, a lack of energy;

sleepiness; drowsiness; confusion; impatience. Others have described fatigue as just don't feel like myself; feeling drained after activities like cooking a meal or taking a shower. Other words used to describe cancer treatment-related fatigue are weary; all-in; worn-out; pooped; low blood; listlessness; no pep; no energy; a strong desire to stop and rest, a strong desire to lie down or sleep.

WHAT HAPPENS WHEN YOU EXPERIENCE CANCER TREATMENT-RELATED FATIGUE?

Fatigue can affect the way you think as well as how you feel. You may need more sleep. You may have trouble paying attention when reading, watching television, even talking with family members. You may find that you are not able to do all the activities you did before cancer treatment.

HERE ARE SOME TIPS TO HELP YOU COPE WITH FATIGUE:

- Plan your day so that you have time to rest.
- Take short naps or breaks, rather than one, long rest period.
- Eat as well as you can and drink plenty of fluids.
- Take short walks or do light exercise if possible. You may find this helps with fatigue.
- Try easier or shorter versions of activities you enjoy.
- Try activities that are less strenuous, like listening to music or reading.
- Keep a diary of how you feel each day. This will help you plan your daily activities.

Join a support group. Sharing your feelings with others can ease the burden of fatigue. You can learn coping hints from talking about your situation. Your nurse can put you in touch with a support group in your area.

- Save your energy for the most important things.
- Become comfortable having others do some things that you usually do.
- See what helps you feel less tired and make those activities a priority for you.

WHEN IS REST NOT THE BEST TREATMENT FOR CANCER TREATMENT-RELATED FATIGUE?

You may be advised to "take it easy" and "get plenty of rest." Sometimes staying in bed over a long period of time can slow your body down and cause you to feel even more tired.

WHAT CAN FAMILY OR SIGNIFICANT OTHERS DO TO HELP WITH CANCER TREATMENT-RELATED FATIGUE?

Do not push yourself to do more than you can do. Ask your family or friends to help you with tasks you find difficult or taxing, like mowing the lawn or grocery shopping. It may be difficult for family members to understand if rest does not make your fatigue go away. Explaining that the fatigue you feel is different from the fatigue you had before treatment may help them understand.

SPECIFIC SYMPTOM MANAGEMENT

TALK TO YOUR ONCOLOGY NURSE OR DOCTOR

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- If you feel confused or cannot think clearly.
- If your fatigue becomes worse.

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PAIN MANAGEMENT

MANAGING CANCER PAIN

Open Communications is the Key to Effective Pain Control:

The key to getting the best pain relief is to talk with your doctor and nurses about your pain. They will want to know how much pain you feel, where it is, and what it feels like. Answering the following questions will help you describe your pain accurately.

1. Where is the pain?
2. What does the pain feel like ? (Ache, Throb, Burn, Tingle)
3. How bad is the pain? Describe your pain on a scale of 0 - 10 with "0" being no pain and "10" being extreme, unbearable pain.
4. What makes the pain worse or better? Sitting, resting in bed, moving, rubbing, etc.
5. If you are being treated for pain now, how well is the treatment working?
6. Has the pain changed since it started?

Causes of Cancer Pain:

There are many causes of cancer pain. Most of the pain of cancer comes when a cancerous tumor presses on bones, nerves, or body organs. Cancer treatment can sometimes cause pain, too.

You may also have pain that has nothing to do with your cancer or its treatment. Like everyone else, you can get headaches muscle strains, and other aches and pains. Because you may be taking medicine for cancer treatment or pain, talk with your doctor and nurses about what to take for these everyday aches and pains. Generally, we want you to avoid over-the-counter drugs which contain aspirin or salicylates. Check labels carefully as many products contain salicylates.

Treating Cancer Pain:

Cancer pain is usually treated with medicine. But, surgery, radiation therapy, and other treatments can be used along with medicine to give even more pain relief.

Many medicines are used to treat cancer pain. Your doctor may give you one or more of them to take. Don't be alarmed if it takes several doses or changes in medication to get your pain completely relieved. Everyone is a unique individual and sometimes it may take a little trial and error to figure out what works best for you.

Pain-medications are usually prescribed as short-acting or long-acting. Short-acting medications usually begin working 1/2 hour after they are taken and are taken more frequently. Short-acting pain medications can be either non-narcotic or narcotic and are sometimes used in combination with long-acting pain medications.

Examples of short-acting pain medications

Non-Narcotic

- 1) Tylenol
- 2) Aspirin
- 3) Ibuprofen (Motrin, Advil)

Narcotic

- 1) Vicoden
- 2) Percocet
- 3) Dilaudid
- 4) Roxanol liquid

Long-acting pain medication provides continuous relief for most cancer pain. Long-acting pain medication does not immediately relieve pain because the medication is released slowly and gradually. Therefore, your doctor may have you take a short-acting pain medication until the long-acting medication takes full effect. Long-acting pain medication does not need to be taken as frequently as short-acting pain medication, but must

be taken on a schedule (whether you are having pain or not). Keeping to the schedule is important to obtain maximal relief from long-acting pain medications.

Examples of Long-acting pain medications:

- 1) M.S. Contin
- 2) Duragesic patches

Side-effects of Pain Medications:

Especially with pain medications that contain narcotics, some patients may experience side effects. The most common side effects are constipation, sedation and nausea.

Constipation:

Constipation can be effectively controlled by medications. It is very important to take this medication on a regular basis. You may need to adjust the amount you take to maintain regular and comfortable bowel movements. Constipation experienced while taking narcotics will not resolve on its own. Following the instructions given to you by your doctor will be important.

Sedation:

Most patients, especially if they have not been sleeping well at night, experience some sedation and drowsiness during the first few days. It may take you several days to actually catch up on sleep once your pain has been relieved. The sedation effect will lessen after you have been on the medication for a few days to a week.

Nausea:

Nausea is usually a temporary side effect of narcotics. Anti-nausea medication can often control the symptoms. Sometimes changing to a different pain medication will be necessary. Notify your nurse if you experience nausea after beginning pain control medication.

Concerns About Addiction:

The fear you or your family may have about addiction could:

- 1) Prevent you from requesting or taking adequate pain medication to control cancer pain;
- 2) Result in your "holding off" from taking medication as long as possible which may adversely affect the amount of pain control you experience; and/or
- 3) Result in your taking lower doses of medication even though pain is not controlled.

Doing any of the above will only result in your delaying pain relief and needless suffering from prolonged pain. Talk to your nurse or doctor about your concerns or fears. They will help you to learn the facts about addiction:

- 1) Addiction rarely occurs in people who are taking pain medication to relieve cancer pain.
- 2) Being on narcotics for a prolonged period of time to control cancer pain does not increase your chance of becoming addicted;
- 3) When the pain stops or is lessened, most people are able to stop or reduce their pain medication without any problems.

Questions and Answers about Cancer Pain Control

Q. Everyone says pain is part of cancer. Shouldn't I just try to learn to live with it?

A. In the Clinical Practice Guidelines called Management of Cancer Pain (Agency for Health Care Policy and Research), current statistics about cancer pain indicate that at the time of diagnosis and at intermediate stages of the disease, 30 to 45 percent of cancer patients experience moderate to severe pain. In patients with advanced cancer, 75 percent of patients have pain. It is important to point out, however, that in approximately 90 percent of patients, cancer pain can be controlled through relatively simple means.

Living with unnecessary pain decreases your overall quality of life. It may make you less active or depressed. You may have difficulty sleeping or working or spending time with family and friends. You may erroneously equate your pain with advancing cancer and begin to feel hopeless. Because you need all of your energy to get through your cancer treatments and get healthy again, living with cancer pain is foolish.

Q. What will the doctor or my health care team need to know about my pain?

A. They will need to know where your pain is, how much pain you feel, and what your pain feels like. They also will want to know what helps the pain and, if you are already being treated for the pain, how well the treatment is working.

Q. Isn't pain hard to describe to someone else?

A. Yes, pain is hard to describe, but you are the only one who can determine how much pain you are in, and you are the only one who can effectively communicate with your doctor or nurse about your need for pain control.

You can describe your pain in many ways. You can use a number scale from 0 to 10, with 10 meaning the worst pain. Or you can use words to describe your pain (for example, mild, moderate or severe, or the worst pain you have ever felt). Try to think of words to describe the pain you are feeling, Is it a tingling, a stabbing pain, an ache or a throb? Write down the words that describe your pain so you will remember to use them when you see your doctor.

Q. What happens if I only have pain at night or during some activity? When I'm at the doctor's office, my pain might not be as severe as it was previously. I don't want to look foolish or have the doctor think I'm a complainer.

A. You have a right to ask for pain relief. For this to happen, you have to tell your doctor about your pain. Don't fail to mention it because you are not in pain at that moment. Keep a record of your pain and take that record with you to your appointment. Keep track of changes in your pain - where it is located, what time of the day it occurs, what it feels like, how severe it is, how long it lasts, what you were doing when the pain first began, and what helps to relieve it. This information will help your health care team develop the most appropriate pain control plan for your pain.

Q. How is cancer pain treated?

A. Pain usually is treated with medicine, but other treatments may be added to your plan if needed. Sometimes radiation therapy is used for pain control. Sometimes treatment may include procedures such as nerve blocks or surgery. Other types of treatment include rest, hot or cold packs, or techniques such as biofeedback, relaxation therapy, music therapy or hypnosis. Finding a good peer support group also may be an asset in dealing with your pain. Your doctor and nurse will recommend the pain control plan that works best for your pain.

Q. The doctor said to take my pain medicine whether I had pain or not. Why shouldn't I save them to use in case the pain gets worse later?

A. This is a mistake that many patients make. The main principle of pain relief is to get the pain under control and prevent it from returning. This can best be accomplished by taking your pain medicine as it is scheduled whether you have pain at that moment or not. Taking your medicine as prescribed allows each dose to become effective before the previous dose has lost its effectiveness. Taking pain medicine on a regular basis leads to better pain control, and you will use a lower total dosage of medication than you would if you only took medication when the pain comes back and is more severe.

Q. If I take too much pain medicine, won't I become used to it? How will they control my pain then?

A. Your body may get used to a certain medication. This is called tolerance. If you develop tolerance to a medicine, the amount of medication can be changed or other medicines can be added. There are many different pain medicines and other techniques to choose from so don't put off using your medications to relieve your pain. If you do find that your pain medicines aren't working as well as they did before, be sure to tell your doctor or nurse.

Q. If I use pain medicine regularly for a long period of time, won't I become addicted to it?

A. Many patients, family members and health care professionals have unreasonable fear of addiction related to taking pain medication. Studies, however, show that getting addicted to pain medicine is very rare. Taking medications for pain due to a disease is not the same thing as abuse of drugs.

Q. What happens if my doctor doesn't address my pain needs or doesn't feel that I'm in as much pain as I feel?

A. You have the right to have your pain believed by your doctor and health care team. You are the single best judge of your own pain severity and only you can describe it accurately. In pain control, as in other areas of cancer survivorship, you need to be a self advocate. If your health care team is not being responsive enough to your pain needs, ask directly how you can help them to better understand your pain. Keep a pain journal that describes the frequency and severity of your pain. Take this journal with you when you go for your appointment. If you still have trouble expressing your needs, take a family member or friend with you, or ask a member of the health care team to intercede on your behalf.

The research literature indicates that cancer pain is often undertreated. It is your responsibility to be certain that your health care team understands your needs for pain control. You also have to be certain that you understand the plan for controlling your pain, and you must alert your health care team if the plan is not working.

Q. Where can I find more information about managing cancer pain?

A. There are numerous sources that provide excellent information about managing cancer pain. Internet Resources.

The National Cancer Institute's Managing Side Effects resource page, part of CancerNet, the NCI's Web site for patients.

NUTRITION

A nutritious diet is important. If your mouth and/or stomach are irritated, you may lose your appetite. The chemotherapy can sometimes directly affect appetite. Trying to maintain good nutrition and your weight will help you feel stronger and recovery more quickly from the treatment.

Be sure to drink plenty of fluids. If you don't feel like eating try Carnation Instant Breakfast Drink, Ensure, Sustacal, Resource, Scandishakes or Boost. For diabetics, use sugar-free Carnation or Glucerna. Add ice cream to make a "shake" and add more calories.

- Eat small, frequent meals.
- Eat high-protein foods.
- Avoid foods that are filling and gas forming (e.g., broccoli, cabbage, fruits and carbonated beverages).
- Avoid large quantities of liquids prior to meals, this may reduce the intake of solid foods.
- Eat slowly to allow the stomach to empty while eating.
- Use alcohol in small amounts or not at all.
- Discuss with your doctor a multivitamin or other supplement
- In some cases your doctor may prescribe a medicine to help stimulate your appetite.
- In some situations, such as radiation involving the mouth or esophagus a feeding tube may be placed into the stomach to allow direct feedings.

Refer to the booklet "Eating Hints for Cancer Patients" (This should be included in your information packet).

PSYCHOSOCIAL SUPPORT

DEPRESSION

Individuals and families who face a diagnosis of cancer will experience varying levels of stress and emotional upset. Fear of death, disruption of life plans, changes in body image and self-esteem, changes in social role and lifestyle, and financial and legal concerns are significant issues in the life of any person with cancer, yet serious depression is not experienced by everyone who is diagnosed with cancer.

There are many myths about cancer and how people cope with it, such as the following: all people with cancer are depressed; depression in a person with cancer is normal; treatments are not helpful; and everyone with cancer faces suffering and a painful death. Sadness and grief are normal reactions to the crises faced during cancer. These reactions will be experienced by all people periodically. Since sadness is common, it is important to distinguish between "normal" degrees of sadness and depressive disorders. A critical part of cancer care is the recognition of the pathologic levels of depression for which treatment should be instituted. Some people may have more difficulty adjusting to the diagnosis of cancer than others, and will vary in their responses to the diagnosis. Major depression is not simply sadness or a blue mood. Major depression affects approximately 25% of patients and has recognizable symptoms that can and should be diagnosed and treated because it has an impact on quality of life.

Normally, the person's initial response to a diagnosis of cancer is brief and may include feelings of disbelief, denial, or despair. This normal response is part of a spectrum of depressive symptoms that range from normal sadness to adjustment disorder with depressed mood to major depression. A restless period marked by increasing turmoil follows, during which time the individual will experience sleep and appetite disturbance, anxiety, ruminating thoughts, and fears about the future. However, studies suggest that at least one-half of all people diagnosed with cancer will successfully adapt. In the adaptation phase, a person begins to internalize and accept the information, prepares for treatment, attempts to adjust family lifestyles around treatment schedules, and tries to maintain a positive outlook for the future.

PSYCHOSOCIAL SUPPORT

ASSESSMENT AND DIAGNOSIS

The symptoms of major depression are a depressed mood for most of the day and on most days; diminished pleasure or interest in most activities; significant change in appetite and sleep patterns; psychomotor agitation or slowing; fatigue; feelings of worthlessness or excessive, inappropriate guilt; poor concentration; and recurrent thoughts of death or suicide. To make a diagnosis of depression, these symptoms should have lasted a minimum of 2 weeks. The diagnosis of depression in people with cancer can be difficult due to the problems inherent in distinguishing biological or physical symptoms of depression from symptoms of illness or toxic side effects of treatment.

If symptoms of depression continue for days or weeks then medication and/or a referral to a health care professional specializing in depression may be necessary. Most anti-depressants take several weeks to maintain a therapeutic effect. Always feel free to discuss any feelings of anxiety, depression or suicidal thoughts with your nurse or doctor.

PSYCHOSOCIAL SUPPORT

SUPPORT GROUPS

In an effort to care for the total well being of the patients of Missouri Cancer Care the physicians encourage you to seek and attend a support group. There are many different support groups for people with cancer. Some are specific for a particular cancer, others are for anyone who has been diagnosed with cancer. We understand that not all support groups are alike, nor are they for everyone, but we encourage participation if possible.

After a diagnosis with cancer, many people find it helpful to talk to someone who has had a similar experience. Sharing your experiences with someone who understands how you feel gives you the chance to express your emotions to someone who has been there.

Studies indicate that support groups may enhance treatment recovery. To benefit from this you could join a support group, surf the Internet for a chat group, or strike up a conversation with the person next to you in the chemo room! Many lasting friendships have been formed this way.

If you are interested in attending a support group meeting talk to your Doctor or one of the nurses about information or recommendations.

PSYCHOSOCIAL SUPPORT

Cancer Treatment and Sexuality

When you were first informed of the diagnosis of cancer, your thoughts probably focused on survival. As soon as a treatment plan was proposed, however, a new question became crucial: How "normal" can your life be, even if the cancer is controlled? What about sexuality?

Sexuality is an important part of the quality of everyday life. Feelings about sexuality influence your zest for living, your self-image, and your relationships with others. Yet patients and doctors often hesitate to talk about the effects of cancer treatment on sexuality.

The most important point to remember is that pleasurable, sexual touching between "loving partners" is always possible, regardless of the physical circumstances, medical history, or surgical procedures. This may sound surprising, especially if you have been feeling depressed or have been sexually inactive for a while. But, it is true: Regardless of the effects of cancer treatment, the ability to feel pleasure from touching almost always remains. Touching from a loved one is a way of sharing intimacy and affection which all human beings need. The lack of intimacy and affection often exaggerates the feelings of loneliness and isolation.

The first step is for you to discuss the topic of sexuality with your doctor or another trusted member of our health care team. Just as you have a right to know how your treatment affects your nutrition, pain, or your ability to return to work, you have the right to know the facts about sexual health.

Sperm Banking:

Chemotherapy and radiation therapy can affect the production and quality of sperm. You may want to consider sperm banking. Please ask your physician or nurse. Arrangement can be made for this process.

Menopause:

Some chemotherapy treatments will affect ovarian function and lead to menopause. Symptoms such as hot flashes, mood changes, vaginal dryness are common and may be helped by medication or other treatment. It is important to discuss these changes with your nurse or doctor.

VASCULAR ACCESS DEVICES

A vascular access device, or central venous catheter, is a temporary or long-term intravenous catheter inserted into one of the major veins of the chest or neck region, or peripherally through a vein in the arm. These are utilized to provide safe, reliable sites to administer intravenous chemotherapy without the repeated trauma of starting a new I.V. each treatment. Depending on the type of device, these are either placed by a surgeon or radiologist, usually as an outpatient.

The choice of catheter depends on the type and length of treatment, type of drugs used, benefits and risks, and/or patient preference.

There are many different types of catheters, both internal and external. Some examples of a temporary external catheter would be:

A PICC line usually placed by a radiologist in the arm. This is a temporary device which may require frequent flushing and weekly dressing changes.

Other external devices frequently used are Groshong or Hickman catheters with single, double, or triple lumens. These also may require frequent flushing and weekly dressing changes.

Any patient with any type of external catheter should have their blood work drawn from this catheter by one of the nurses in our office. If you are called to the lab in our office for blood work please notify them that you have an external catheter and they will notify a nurse to draw your blood.

An implanted port, usually referred to in our office as a port-a-cath, is inserted by a surgeon, and completely implanted under the skin. Once the incision has healed, there are usually no restrictions for a patient with a "port". These are accessed by a nurse using a sterile technique to minimize the risk of infection. To minimize discomfort with accessing, the site may be sprayed with a topical spray which freezes or numbs the site, or a cream may be ordered to be applied at home at least one hour before coming into the office. Once all of your treatments have been completed your port will need to be flushed approximately every six weeks. We ask that patients with an implanted port have their weekly blood tests drawn by the lab technician either with a fingerstick or venipuncture. This is to minimize the risk of infection associated with frequent accessing of your port.

As with any surgical procedure, there are risks involved with any procedure and these should be discussed with you by your surgeon. A chest x-ray will be performed after the procedure to verify placement. Depending on the type of procedure there may be sutures involved and/or temporary swelling at the site of insertion.

RESOURCES

What is PDQ?

PDQ is a computer system that gives up-to-date information on cancer and its prevention, detection, treatment, and supportive care. PDQ is a service of the National Cancer Institute (NCI) for people with cancer and their families and for doctors, nurses, and other health care professionals.

To ensure that it remains current, the information in PDQ is reviewed and updated each month by experts in the field of cancer treatment, prevention, screening, and supportive care. PDQ also provides information about research on new treatments (clinical trials), doctors who treat cancer, and hospitals with cancer programs. The information in this summary is based on the summary for health professionals on this topic and addresses the special needs of patients with cancer and their families during cancer treatment.

How to use PDQ?

PDQ can be used to learn more about current care for patients with cancer. You may find it helpful to discuss this information with your doctor, who knows you and the facts of your disease and can help answer questions and ease concerns. PDQ can also provide the names of additional health care professionals who can help you and your family during the treatment of your disease.

If you want to know more about cancer and how it is treated, or if you wish to know about clinical trials for your type of cancer, you can call the NCI's Cancer Information Service at 1-800-422-6237, toll free. A trained information specialist can talk with you and answer your questions.

RESOURCES

Information for Patients

**National Institutes of Health, National Cancer Institute Publications:
Office of Cancer Communications
Building 31, Room 10A24
Bethesda, MD 20892
(1-800-422-6237)**

Eating Hints for Cancer Patients: NIH Publication No. 94-0279, Revised June 1994

Chemotherapy and You: NIH Publication No. 94-1136, Revised July 1993

Radiation Therapy and You: NIH Publication No. 95-2227, Revised October 1993

Facing Forward, A Guide for Cancer Survivors: NIH Publication No. 94-2424, Revised July 1994

**American Cancer Society, National Cancer Institute Publications:
Office of Cancer Communications
Building 31, Room 10A24
Bethesda, MD 20892
(1-800-422-6237)**

Questions and Answers About Pain Control, A Guide for People with Cancer and Their Families:
NIH 92-2000M-No. 4518

Books:

The Race is On, One Step At A Time: Nancy G. Brinker, The Summit Publishing Group,
Arlington, TX, 1995.

Most of these books are available in our office. Just ask and we will get you one.

GLOSSARY OF MEDICAL TERMS

Acute: Occurring suddenly or over a short period of time.

Adjuvant Therapy: Anticancer drugs or hormones given after surgery and/or radiation to help prevent cancer from coming back.

Alopecia: Hair loss.

Analgesics: Medicines used to relieve pain.

Anemia: Having too few red blood cells. Symptoms include feeling tired, weak, and short of breath.

Anorexia: Poor appetite.

Antibody: A protein made by the body's immune system to neutralize harmful foreign substances (antigens) such as bacteria, viruses, or cancer.

Antiemetic: A medicine used to prevent or control nausea and vomiting.

Benign: A term used to describe a tumor that is not cancerous. Usually, a benign tumor requires surgical removal but no further treatment.

Biopsy: Removal of tissue from the body for microscopic examination to determine if cancer cells are present.

Blood count: The number of red blood cells, white blood cells and platelets in a sample of blood. This is also called a complete blood count or CBC.

Bone marrow: The inner, spongy tissue of bones where blood cells are made. A bone marrow aspirate is a test in which a needle is inserted into the bone marrow and a syringe is used to create suction to remove a specimen of marrow (it looks much like a small sample of blood taken from a vein). A bone marrow biopsy is a test in which a special needle is inserted into the bone marrow and a portion of the marrow is removed.

Bone Scan: An image of the bones taken after injecting radioactive dye to help determine if cancer has spread to the bones.

Cancer: A general name for more than 100 diseases in which abnormal cells grow out of control; a malignant tumor.

Catheter: A thin flexible tube through which fluids can enter or leave the body.

CAT Scan or CT Scan: A computerized X-ray system that delivers very detailed pictures of a body part or organ.

Central Venous Catheter (CVC): A special thin, flexible tube placed in a large vein. Also called a CVC, there are basically two types: external and ports (see appropriate definitions). It remains in the large vein until there is no longer a need to deliver or withdraw fluids.

Chemotherapy: The use of drugs to treat cancer.

Clinical trials: Medical research studies conducted with volunteers. Each study is designed to answer scientific questions and to find better ways to prevent or treat cancer.

Colony-stimulating factors: Substances that stimulate the production of blood cells. Treatment with colony-stimulating factors (CSF) can help the blood forming tissue recover from the effects of chemotherapy and

radiation therapy. These include granulocyte colony-stimulating factors (G-CSF) and granulocyte-macrophage colony stimulating factors (GM-CSF).

Cycle of Chemotherapy: A schedule of chemotherapy treatment over a period of time (usually days). Each cycle includes the chemotherapy treatment period and a rest period for the patient. The cycle is repeated until the entire course of prescribed treatment is completed.

Dose: The amount of medication the doctor prescribes for a patient.

Edema: Abnormal accumulation of fluid that causes swelling in tissues of the body. Usually occurs in hands, feet or ankles.

Gastrointestinal: Having to do with the digestive tract which includes the mouth, esophagus, stomach, and intestines.

Hematocrit (Hct): A measure of the volume of red blood cells contained in a specific volume of blood. If low, red blood cells may be replaced with a transfusion.

Hematologist: A doctor specializing in the treatment of disorders and/or diseases of the blood and/or blood forming organs.

Hemoglobin (Hgb): The iron-containing pigment of red blood cells which carries oxygen to the tissues. If low, red blood cells may be replaced with a transfusion.

Hormones: Natural substances released by an organ that can influence the function of other organs in the body.

Hospice: A program of caring for patients who are terminally ill with a focus on improving quality of life.

Immune system: The body mechanism that fights disease by recognizing and neutralizing foreign cells.

Infusion: Slow and/or prolonged intravenous delivery of a drug or fluids. An infusion will flow into the vein by gravity or by the assistance of a mechanical infusion pump.

Injection: Using a syringe and needle to push fluids or drugs into a vein, artery, muscle, body cavity, spinal fluid, or under the skin. Often called a "shot".

Intravenous (IV): Into a vein.

Local anesthetic: A drug that blocks pain sensation only in the region where it is applied. Local anesthesia can be given as a cream or ointment applied to the skin or as a subcutaneous injection.

Malignant: Term used to describe a cancerous tumor.

Metastasis: Term to describe when cancer cells break away from their original site and spread to other parts of the body.

MRI (Magnetic Resonance Imaging): Creates body images using a magnetic field and radio waves, rather than X-ray; produces images similar to a CT scan, but with much greater definition.

Mucositis: Sores or inflammation of the mucous membranes (lining) of the mouth.

MUGA Scan: Checks efficiency of heart to see how effectively it is contracting. Painless procedure with no side effects.

Myelosuppression: A decrease in the ability of bone marrow cells to produce blood cells, including white cells, red cells, and platelets.

Neutropenia: A decrease in the number of neutrophils, a type of white blood cell. The doctor may order colony-stimulating factors to increase the rate of production of neutrophils.

Nuclear medicine: Another term for scans or tomograms.

Oncologist: A doctor specializing in the treatment of cancer.

Palliative care: Treatment to relieve, rather than cure, symptoms caused by cancer. Palliative care is aimed at helping people live more comfortably.

Per os (PO): By mouth, orally.

Platelets: Special blood cells that help stop bleeding.

Port: A small plastic or metal container surgically placed under the skin and attached to a central venous catheter inside the body. Blood and fluids can be delivered or removed from the body through the port using a special needle.

Protocols: The guidelines that specifies how a clinical trial will be conducted.

Radiation therapy: Cancer treatment with radiation (high-energy rays).

Recurrence: The return of cancer after its apparently complete disappearance.

Red blood cells (RBC): Cells that supply oxygen to tissues through the body. A CBC measures the amount of RBCs in the blood. Specifically, the CBC measures the volume of RBCs in comparison to other blood components and the hemoglobin measures the oxygen carrying capacity of the RBC. If either or both of these measures are low, the doctor may order a transfusion of RBC or a drug to stimulate RBC production.

Remission: The partial or complete disappearance of signs and symptoms of disease.

Side effect: A secondary, unintentional and usually undesirable effect from a drug or other treatment.

Stomatitis: Sores on the lining of the mouth.

Subcutaneous (SQ or SC): Under the skin.

Systemic: A term meaning throughout the body.

Thrombocytopenia: A decrease in the number of platelets in the blood. If very low, the doctor may order platelet transfusions.

Transfusion: The replacement of one, several or all blood cells by infusion into a vein. Red blood cell and platelet transfusions are most common.

Tumor: An abnormal growth of cells or tissues. Tumors may be benign (noncancerous) or malignant (cancerous).

Tumor markers: Substances found in abnormal amounts in the blood, other body fluids, or in tumor tissue which indicates abnormal tumor growth is present.

Tumor response: How a tumor is affected by the treatment given.

Ultrasound: A way to locate and measure solid tumors using very high frequency sound waves.

White blood cells (WBC): The cells which fight infection. There are several types of WBC: Neutrophils, lymphocytes, basophils, eosinophils, monocytes. Each has a specific function in fighting off infections.