

The Lymphoma/Myeloma Center's

Tips for Managing Drug Therapy



**PATIENT
EDUCATION**

Lymphoma/Myeloma Center

716-845-1642

Center Hours: 8 a.m. – 5 p.m.

Roswell's main number: 716-845-2300 (Available 24/7)

When to Call

Call us immediately if you have a fever of 100.4°F (38°C) or higher.

Call us as soon as possible if you have:

- blood in your urine or stool or a persistent bloody nose
- severe nausea even though you took your prescribed medication
- pain or difficulty swallowing, urinating (peeing), or moving your bowels
- cancer-related pain even though you took your prescribed pain medication
- worsening dizziness, weakness, or fatigue
- any falls

The Lymphoma/Myeloma Center's Tips for Managing Drug Therapy – A Companion Guide to *Taking the Lead*



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Welcome to the Lymphoma and Myeloma Center


Introduction

- *Taking the Lead* provides tips on how patients starting drug therapy can become an active partner in their care, lessen the impact of treatment on daily life, and minimize side effects.
- This book gives you additional information that is specific to patients being treated in our center.
- Please feel free to ask any questions. The end of this book will contain blank pages where can
- Write down questions you want to ask your care team.
- Roswell Park offers a wide range of supportive services such as physical and occupational therapy, registered dietitian nutritionists (RDNs), social workers, a patient and family resource center, the Cancer Coach program, our online community, and help quitting tobacco. See *Resources and Support* on page 24 or in the Taking the Lead booklet. Roswell Park also has a separate Resources and Support booklet.
- Patient Education brochures on managing specific side effects and support resources are available in our Chemotherapy and Infusion Centers, The 11 Day Power Play Cancer Resource Center (on the 1st floor of the main hospital by the tower elevators), and in the health library on the “MyRoswell” patient portal.

Worth Repeating

Everyone is different. Always check with your healthcare provider before starting any exercise or activity program, making big changes in your diet, or using any type of integrative or complementary therapy. (Vitamins, supplements, massage, acupuncture, etc.)

What the Symbols Mean

-  Key point
- ✓ Actions you can take
- General information or recommendation



Common Concerns for Patients Starting Drug Therapy - Tips from Patients

- ✿ Just the thought of starting drug therapy may be overwhelming. You may find your feelings and emotions swing widely over the upcoming months. It is perfectly normal to feel a whirl of emotions such as sadness, anger, and frustration about the disease and the side effects of treatment.
- ✿ It is important to develop good communication with family members, friends, and your health care team to help you deal with your experiences and the emotions that come along with them.
- ✿ **This booklet was created to remind you that you are not alone; but your experience is unique.** If you have any questions or concerns, please know the Roswell Park staff is here to guide and support you.

What Can I Expect from Drug Therapy?

It is likely that you will have questions and concerns about what to expect. Here are some frequently asked questions – and answers - to help lower your anxiety and prepare you for your treatment.

You will also find some suggestions from other patients that have gone through drug therapy. Remember, your experience may be quite different from other people, even if they have the same type of cancer and treatment as you.

Your healthcare team is here to work with you to prevent and manage side effects. However, they can only help you if you keep them up-to-date on how you are feeling.

Anxiety and Restlessness

"Go in with a good attitude. Consider chemotherapy spa treatment for the insides of the body. Let the medicine cleanse your inner skin."

"Don't look at a watch or cell phone clock. Read, go online, listen to (music, books, or podcasts), do puzzles, sleep, knit/crochet, watch TV, bring a loved one/friend to chat with you".

"It is hard in the beginning, but it opens up your eyes. You begin to see the world differently."

Cancer and treatments can be very stressful for you and for your loved ones. It may cause you to feel anxious before, during, or even after treatment. Many times, it may feel like you cannot relax and enjoy your life as you did before treatment.

Symptoms of Anxiety



- Constant worrying or obsession
- Muscle aches
- Restlessness, trembling
- Nausea/vomiting
- Trouble sleeping
- Fatigue or feeling tired
- Irritability
- Shortness of breath

Relaxation techniques can help calm your mind and help you mentally focus. They can help you manage anxiety, pain, and other physical symptoms that can affect your response to treatment.

These techniques significantly improve the quality of life for some people. You can use the suggestions below to help you relax, stay calm, and keep a clear head for making treatment decisions.

Tips for Dealing with Anxiety and Restlessness

Deep-Breathing Exercises

Anxiety and stress can make us take short, shallow breaths. Shallow breathing does not allow enough oxygen to enter our bodies and can make us more anxious. As you practice deep breathing, imagine a peaceful setting.

- ✓ Here is a simple breathing exercise: Take in a deep breath and hold it for several seconds. Exhale slowly. Repeat 1-2 more times.

Meditation

Repetitive prayers are a form of meditation. Choose a word that is important to you such as "peace", "love", or "hope". Focus on this word and if you find your mind wandering, focus back on the word. It is best to do this in a quiet environment and without distractions.

Guided Imagery

- ✓ This technique combines deep breathing and meditation. As you practice your deep breathing, imagine yourself in a peaceful setting. Continue deep breathing until you feel relaxed.
- ✓ Once you are relaxed, create a “wakeful dream” in your mind. Picture your stress being washed away by a gentle rain or sitting outside on a beautiful day with your body gaining strength from the sun shining down on you.
- ✓ Try practicing these relaxation techniques while listening to music or sounds from nature.
- ✓ Express what you are feeling. Record your emotions through photography, journaling, drawing, painting, or music.
- ✓ Share your feelings with people who you trust.
- ✓ Join a support group, the online Roswell Community, or a “buddy” program – you do not have to face this alone!
- ✓ While you are a beginner, practice at times when your stress level is low to moderate.
- ✓ If you become frustrated during a practice session, stop, and try again later. By practicing these techniques regularly, you can learn to use the power of your mind to decrease anxiety, lessen discomfort, improve sleep, and increase your sense of well-being.



If this is your first time using any of these relaxation techniques, don't get discouraged! It may take a bit of time and practice to reach the point where you can use these techniques successfully in high stress situations.

Nausea and Vomiting

“Do not be afraid to take your medications to help deal with nausea.”

“If you are not feeling good, tell them (your doctors and nurses) and they will give you something right away.”

Tips for Managing Nausea and Vomiting

- ✓ Do not wait to tell your doctor or nurse that you have nausea. There are medications (anti-emetics) that you can take before your infusion to prevent or reduce nausea.
- ✓ There are many medications (and combinations of medications) that can be tried. Please be patient while you and your team find which ones work best for you. Give your doctor feedback about how they are working, or if a medication no longer works for you.
- ✓ Try eating smaller meals more frequently during the day instead of 3 large meals a day.
- ✓ Eat and drink slowly.
- ✓ If you have nausea or vomiting, try clear liquids first. If they stay down, try other liquids, and then move to bland foods such as rice, applesauce, and bread.



You must stay hydrated during treatment. Nausea and vomiting can lead to dehydration. Dehydration occurs when your body does not have enough water/fluids to function normally. **Severe dehydration can have serious consequences.**



Drink plenty of water and other nonalcoholic beverages – 3 to 4 quarts/liters every day. Products such as Pedialyte® will replace fluids and electrolytes such as sodium (salt) and potassium.

Body Image



"Hair will come back in time."

"Ordering soft or pureed food helped me keep the weight on, especially when I was feeling nauseous."

Tips for Dealing with Body Image

- ✓ You may be worried about hair loss. If you do lose your hair, it may take about 6 -12 months to grow back. Sometimes new hair will grow back a different texture or color. These changes may last only a short time, or they may be permanent.
- ✓ Talk to your doctor or nurse about getting a wig before you have lost all your hair; it will make it easier to match your natural color. Wigs are available at the Elevate Salon on the first floor of the Clinical Sciences Center. Cancer patients can receive a one complimentary wig and head covering. Having a wig ready before you have lost your hair can help you feel more prepared and more in control.
- ✓ Some drug therapies can cause skin problems such as dry, itchy skin, rashes, acne, peeling, etc.
 - Wash with a simple, detergent-free soap.
 - Use a gentle skin moisturizer that does not contain any alcohol products.
 - Use lukewarm shower for washing, showering, or bathing instead of hot water.
 - If you get a rash, do not put anything on it until you have gotten permission from your doctor.
- ✓ Weight changes are not a problem for everyone, but when they occur, they can be particularly hard for some people to handle. During treatment, you must focus on your goal. Some people lose their appetite, mouth sores can make eating difficult, and sometimes food just does not taste the same. These factors can make it a challenge to maintain your weight through treatment.
- ✓ Other people struggle not to gain weight as medications make their bodies retain fluid, increase appetite, or make them too tired for physical activity.
- ✓ Discuss your weight changes with your doctor. Ask what you can do to control your weight. If you need to make changes in your diet, ask for a referral to meet with a Roswell Park dietitian.
- ✓ If the weight change affects your self-image, a support group may help you learn how to cope with the changes.



Forgetfulness

"Keep yourself entertained, read, do puzzles, or listen to music. It will help keep your mind sharp."

"Close your eyes and sleep. Getting a good rest will help your memory, especially because you are woken up several times during the night."

During your treatments, you may develop new problems with memory, concentration, and/or attention span. You may feel that you are just not functioning as you used to before treatment. "Chemobrain" is a common term for these changes, though they may occur from other types of treatment as well, such as radiation therapy. Currently the exact cause is not known, but researchers are studying the problem in hopes of finding effective treatments.

Symptoms

- Being confused
- Memory loss
- Short attention span
- Inability to focus on daily tasks
- Having difficulty finding the right word



Managing Chemobrain

- **Write it down.** For example, write grocery or "to-do" lists in a notebook. It may also be helpful to record highlights from a doctor's visit or lab results.
- **Use a personal planner or wall calendar.** This will help you remember appointments and important dates. Include details (time, place, what to bring).
- **Proofread or "double-check" information.** This gives you the chance to review your words so the reader will be able to understand what you want to say.
- **Minimize distractions to help stay focused.** Too many things are going on at once can be distracting. For example, if you are having a conversation, it may be helpful to turn off the television. Keeping your environment neat and clean may be less distracting while reducing your risk of tripping or falling.
- **Be open with family and friends.** Sharing information about what you are going through is a private decision. Yet, it can be helpful to have the support of others through tough times. Family and friends may help remind you of things you may have forgotten.
- **Share your symptoms with your doctor or social worker.** Since your symptoms may cause anxiety or feelings of sadness, it is important to share them with a healthcare provider.



Complete Blood Count (CBC)

✿ **The most common lab test done during treatment is called a complete blood count, or CBC.** A CBC tells your cancer care team about the cells in your blood. It measures 3 basic types of blood cells:

- Red blood cells
- White blood cells
- Platelets

Each kind of cell has a special purpose. And each can be harmed by cancer and cancer treatments.

White Blood Cells (WBCs)

WBCs fight infection. There are many types of white blood cells and they fight infection in different ways. The most important infection-fighting WBC is the neutrophil (NEW-truh-fil). The number doctors look at is called your absolute neutrophil count (ANC). A healthy person has an ANC between 2,500 and 6,000.

When the ANC drops below 1,000 it is called neutropenia (new-truh-PEEN-e-uh). Your doctor will watch your ANC closely. The risk of infection is much higher if the ANC goes below 500.

Red Blood Cells (RBCs)

RBCs carry oxygen to, and carbon dioxide away from, the cells in your body. The CBC measures red blood cells in many ways, but the simplest measure is either:

- hemoglobin (Hgb), the part of each RBC that carries oxygen -or-
- hematocrit (Hct), the percent of RBCs in the blood

When the Hgb and Hct values fall too low, it's called anemia (uh-NEE-me-uh). Anemia may cause fatigue, pale skin, dizziness, shortness of breath, and a fast heartbeat. If hemoglobin falls too low, a blood transfusion may be needed.

Platelets (PLTs)

Platelets help control bleeding. You may bruise or bleed easily when your platelet levels are low. Platelets in a healthy person range from 150,000-450,000. When your platelet count falls below normal, it is called thrombocytopenia (throm-bo-SY-tuh-PEEN-e-uh). The risk of serious bleeding goes up when platelet levels drop below 20,000. A transfusion may be needed.



Managing Side Effects of Drug Therapy

Side Effect	What You Can Do	Reason to Call Us
Infection	<ul style="list-style-type: none"> ✓ Take your temperature every day ✓ Watch for symptoms of infection: <ul style="list-style-type: none"> • muscle aches • headache • cough • difficulty breathing • pain, burning or blood during urination • urinating more or less often than usual • unusual discharge from your vagina or penis • any areas with pus formation, redness, heat, or swelling 	<ul style="list-style-type: none"> • Your temperature is 100.4°F (38°C) or higher or you have any sign or symptom of infection
Allergic Reaction	Watch for: <ul style="list-style-type: none"> • rash • itching • hives • palpitations • dizziness • swelling or tingling in mouth/throat 	<ul style="list-style-type: none"> • Any sign of an allergic reaction
Diarrhea	Watch for: <ul style="list-style-type: none"> • bowel movements (BMs) looser or 2-3 times more frequent than normal (for you) • changes in stool color or firmness • increase in your ostomy output 	<ul style="list-style-type: none"> • Increased stomach cramping • Diarrhea lasting more than 24 hours • Diarrhea that contains blood or that is accompanied by severe cramping or pain

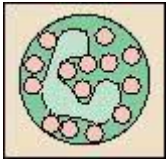
Side Effect	What You Can Do	Reason to Call Us
Constipation	Watch for: <ul style="list-style-type: none"> • bowel movements firmer or harder to pass than normal • feeling bloated or less hungry • increased stomach pain or cramps 	<ul style="list-style-type: none"> • It has been more than 2 days since you normally would have had a bowel movement • You need a laxative or stool softener to “go” and you didn’t before treatments
Upset Stomach, Vomiting	<ul style="list-style-type: none"> • Know that your treatment may change your interest in food and odors may increase nausea • Note the timing of any vomiting • See page 8 	<ul style="list-style-type: none"> • You cannot eat or keep food down for 24 hours • You vomit more than three times in one day • You have projectile vomiting (vomiting with great force) • You have difficulty swallowing
Mouth Sores	<ul style="list-style-type: none"> ✓ Brush gently ✓ Do not use mouthwash with alcohol in it ✓ See your dentist regularly ✓ Watch for: <ul style="list-style-type: none"> ○ redness ○ tenderness ○ swelling of your lips, gums, or tongue ○ changes in your saliva, or dryness in your mouth 	<ul style="list-style-type: none"> • You have pain or discomfort when you eat or drink • You have open sores, blisters cracking, or bleeding on your lips, gums, mouth, or throat
Nervous System Changes	Watch for changes in: <ul style="list-style-type: none"> • vision • hearing • touch • balance • walking • fine motor ability (such as picking up small objects and buttoning clothes) 	<ul style="list-style-type: none"> • Muscle weakness • Numbness or tingling in your arms, legs, hands, or feet • Loss of balance or clumsiness • Confusion • Dizziness • Trouble breathing cold air • Trouble touching cold items

Side Effect	What You Can Do	Reason to Call Us
Hair, Nails, Skin	Watch for: <ul style="list-style-type: none"> • small red dots on your skin • skin rashes • brittle nails • pale or red skin • itching or peeling skin 	<ul style="list-style-type: none"> • Skin color changes • Redness, swelling, or soreness on the spot where you receive your medicine
Fluid Imbalance, Edema (Swelling)	<ul style="list-style-type: none"> • Weigh yourself daily • Measure “around” at the same spot on each ankle, wrist, and calf, and around your neck at the start of treatment and regularly after treatment • With your fingers push gently on an area of your skin for 15 seconds and then quickly remove your fingers. Edema will cause the skin to remain dimpled after you’ve removed your fingers. Watch for: <ul style="list-style-type: none"> • shoes feeling tight • can’t remove your rings 	<ul style="list-style-type: none"> • Weight gain of 2-3 pounds a day for two days in a row (you may see a weight gain before you can see the edema (swelling)) • Urinating less than 1 cup per day • If swelling becomes excessive
Bleeding	<ul style="list-style-type: none"> • Monitor the color of your bowel movements Watch for: <ul style="list-style-type: none"> • easy or excessive bruising 	<ul style="list-style-type: none"> • Unusual bruising • Bloody nose • Bleeding in your mouth • Blood in your urine, bowel movement, or vomit (blood in bowel movements or vomit may look black) • Coughing or spitting up blood
Musculoskeletal		<ul style="list-style-type: none"> • Have severe muscle cramps or bone pain

Fatigue, Mood	<ul style="list-style-type: none"> • An increased need to rest 	<ul style="list-style-type: none"> • You find it hard to function because you are so tired • You feel exhausted even though you have had enough sleep • You feel so anxious or sad • that it is hard to get through the day
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Recognize and Report Your Side Effects Early!

- ✓ Take control of your life by learning about your condition, understanding your treatment, and knowing how to manage side effects. Talk openly and honestly with your healthcare team.
- ✓ Staying in touch with your body during treatment can help you spot side effects early. Report them right away to your doctors and nurses. Preventing side effects, or treating them early, can help you feel as good as possible during treatment.
- ✓ Use a journal or calendar to record the details of your treatment including instructions from your doctor and nurses, how you are feeling, and notes on your progress.



Precautions for Patients at High Risk for Infections (Neutropenic Precautions)

Important!

- These precautions are for adults who have severe neutropenia and a high risk of infection. This includes patients with blood cancers who are expected to be severely neutropenic for more than 10 days.
- **Your doctor will let you know what neutropenic precautions, if any, you need to follow during your treatment.**

Thank you.

Neutrophils are a type of white blood cell that helps your body fight infections. When your neutrophil count drops below a certain level, you are considered to have neutropenia or be neutropenic. When you have neutropenia, you are at higher risk for infections.

A number of things can cause neutropenia, including drug therapy for cancer. Not everyone with neutropenia has the same level of risk for getting an infection. Neutropenia can range from mild to severe.

Several factors can affect your risk level, such as:

- the type of cancer you have
- the kind of anticancer treatment(s) you are receiving
- any other medical problems you may have
- how low your neutrophil count has fallen (severity)
- how long you have had neutropenia

These recommendations are a general guide to help protect you from infection until your own immune system can go back to doing its job. Talk to your doctor about your risks of infection and the specific precautions you need to follow.

General Recommendations

- ✓ Take your temperature, by mouth, 4 times a day. **Call your doctor immediately if your oral temperature is above 100.4°F (38°C).**
- ✓ Try to do some low-impact exercise every day. Walking and swimming are both low-impact.
- ✓ Always talk with your doctor before you get any vaccine. Some vaccines contain live viruses. If your white count is low, this type of vaccine may make you sick.
- ✓ People getting drug therapy should avoid naturopathic and other alternative medicines. If you have questions about any of these products or treatments, discuss them with your doctor before trying them.
- ✓ Discuss any travel plans with your doctor.

Do Not...

- ✓ use a rectal thermometer or a rectal suppository
- ✓ get close to people who have a cold or any contagious disease such as chicken pox or flu
- ✓ participate in activities that may cause injury such as biking, rollerblading, skiing, or skating

Avoid

- ✓ fresh flowers, plants, and freestanding water
- ✓ public transportation, when possible (If you can't avoid it, use it when it is less crowded.)
- ✓ areas where there may be a lot of dust or mold such as construction sites, damp
- ✓ basements, etc.

Medications

Depending on your medical history and the type of drug therapy you will receive, your doctor may prescribe an injection of a Colony-Stimulating Factor, or CSF, such as filgrastim/Neupogen® or pegfilgrastim/Neulasta®. This injection can shorten the time that you have neutropenia. Most people now leave their drug therapy wearing an on-body injector that dispenses the medication at the right time. The on-body injector means you do not have to return for an injection. Your doctor may also prescribe antibiotics to prevent infections.

Do Not...

- ✓ **use aspirin, acetaminophen, or any other medicine** to reduce a fever without checking with your doctor first.

Avoiding Infection and Injury

- ✓ Always wear shoes when outside and shoes or slippers when indoors to prevent cuts on your feet.
- ✓ Take care to avoid cuts or nicks when using scissors, needles, or knives.
- ✓ Women should use sanitary napkins, not tampons.
- ✓ When possible, your doctor should be contacted before you have dental work performed. If you have emergency dental work, you must tell your dentist that you are receiving drug therapy and give them your most recent white blood cell count.

Do Not...

- ✓ share utensils (forks, spoons, and knives), glasses, or dishes with anyone
- ✓ share towels with anyone. Use a fresh towel every time you bathe or shower.
- ✓ use straws more than once. Be careful not to scrape or cut the inside of your mouth with the straw.
- ✓ provide direct care for any type of pet. You must not clip their nails, groom them, or bathe them. Have someone else clean birdcages, litter boxes, or fish tanks.
- ✓ vacuum or dust (Leave the room while someone else performs these tasks.)
- ✓ use any personal care or health products that could damage mucous membranes including tampons, rectal or vaginal suppositories, enemas, douches, rectal thermometers, etc.

Mouth and Oral Care

- ✓ Use a soft toothbrush and run it under warm water to make it even softer. If you need something softer, use an oral sponge (toothette), which is like a Q-tip, but it has a sponge on the end instead of cotton.
- ✓ Take good care of your teeth and mouth – brush your teeth gently before and after meals (about 3 to 4 times per day).
- ✓ You may gently floss your teeth daily if you can do so without injuring your gums.
- ✓ Use an alcohol-free, peroxide-free, antiseptic mouthwash such as Biotene® every day.

Skin Care

- ✓ **Washing your hands with soap or an antimicrobial product is the single most important action you can take to prevent infection.** Wash your hands often, before and after eating, and after using the restroom.
- ✓ Wash daily. Gently pat your skin dry – do not rub.
- ✓ Clean your genital and rectal areas well after urination, bowel movements, and sexual activity. Women should clean the area from front to back.

Skin Care - continued

- ✓ Protect your hands. Wear rubber gloves when doing dishes, oven mitts when cooking/baking, and protective gloves in any situation where you may be scratched or cut. (Gardening is not recommended for patients who are neutropenic).
- ✓ Use deodorant instead of antiperspirant. Antiperspirants can block your sweat glands, which could increase your risk of infection.
- ✓ Use an electric razor instead of a razor with a blade to avoid breaks in the skin.
- ✓ Avoid sunburns. Use a sunscreen with an SPF of 30 or higher.
- ✓ If you get a cut or scrape, clean it right away with soap and water. Use an antiseptic cream and then keep it covered with a bandage until the area is healed. Keep the bandage clean and dry. Replace the bandage if it gets dirty or wet.

Do Not...

- ✓ chew, cut, or pick at the cuticles around your nails
- ✓ have cosmetic work done on your nails that could injure your cuticles or skin
- ✓ wear artificial fingernails or nail extenders
- ✓ squeeze or scratch pimples

Sexual Activity

If your doctor has told you that sexual activity is allowed, please follow these guidelines to lower your risk of infection:

- ✓ Unless you are in a long-term monogamous relationship, consider avoiding sexual activity while neutropenic.
- ✓ Avoid sexual practices that could result in oral exposure to stool or that could cause injury to tissue, such as anal sex.
- ✓ Consider using a latex condom to reduce the risks of getting an infection.
- ✓ If you need lubrication during sexual activity, use a water-soluble lubricant like K-Y® jelly.
- ✓ Report any signs of infection such as discharge, itching, odor, bleeding, or pain during intercourse.

Food and Digestion

- ✓ Wash all fresh fruits and vegetables before you eat or drink them.
- ✓ Municipal tap water is fine to drink. If you do not have access to municipal tap water, use boiled water or bottled water that is labeled distilled, or that has been treated with reverse osmosis or an absolute one-micrometer filter.
- ✓ Prevent constipation. Drink plenty of fluids and consider using a stool softener to help prevent straining.
- ✓ Refer to Roswell Park's Low Microbial Diet booklet for specific food guidelines, a list of bottled waters that are safe to drink, and food safety guidelines for dining out.

Do Not...

- ✓ drink from public water fountains
- ✓ take a suppository or enema unless you have discussed it with your doctor first
- ✓ eat expired or spoiled foods
- ✓ eat raw or undercooked meat, eggs, or fish
- ✓ eat milk or cheese that is not pasteurized
- ✓ uncooked herbs and spices

When to Call Your Doctor

If you have any of the following symptoms, please call your doctor immediately.

- **Fever of 100.4°F (38°C) or higher**, shaking chills, or sweats (sometimes, fever is the only sign of infection)
- Redness, pain, tenderness, swelling, or drainage:
 - at an IV or central line site
 - on irritated skin, including the armpit, buttocks, mouth, genitals, or anal area
 - from any tube (feeding tube, urinary catheter, drainage tube), cut, or sore
- Pain or burning with urination
- Urine with an unusual odor; or vaginal itching or discharge
- Sores, white patches, or swelling in your mouth; your gums change color
- Difficulty breathing, a feeling of pressure in your chest, congestion, or productive cough (coughing up mucus or phlegm)
- Diarrhea or changes in odor, texture, or frequency of bowel movements
- Feeling as if you are coming down with the flu, even if you have none of the other symptoms listed

More Information about Neutropenia

- White blood cells (WBC), red blood cells (RBCs), and platelets are produced by your bone marrow.
- Neutrophils are the “first responders” of your immune system when you are injured or when a bacteria, virus, or other foreign substance invades your body.
- Neutrophils only live for 7-12 hours. Your bone marrow must continually make more to replace the older neutrophils that have died.
- Some cancer treatments may temporarily slow down the activity in your bone marrow and prevent your body from making new blood cells.
- Being neutropenic means you are more susceptible to infections.
- Taking basic precautions can reduce the chance of developing an infection during neutropenia.
- Your physician factors in any other health problems you have when deciding whether neutropenic precautions are needed and how strict those precautions should be.
- **Signs of infection may be reduced or absent during neutropenia.** For example, you could get an infection in your skin or in your lungs (pneumonia), but not have any pus or sputum. Sometimes, fever is the only sign of infection. Common sites of infection in people with neutropenia include the digestive tract (sores or ulcerations, diarrhea), lungs (cough, shortness of breath), urinary tract (painful or frequent urination, cloudy or bloody urine), skin, and mucus membranes.
- Always check with your doctor about your white blood cell count and your current risk of infection. If you do have neutropenia, follow the precautions recommended by your doctor for the greatest benefit. Ask your doctor how long you should follow these recommendations.



Intimacy and Cancer

- Healthcare providers may overlook the intimacy needs of adults with cancer. Discuss your concerns with your doctor or nurse. Though it may be uncomfortable to start the conversation, it will be worth it if you learn about ways to improve your relationship and lessen stress.
- Cancer and its treatments can have a big effect on your quality of life. This goes for both people with cancer and their family members, especially their intimate partners. It is important for the partner without cancer to tell the healthcare provider about their sexuality and intimacy concerns as well.

Concerns About Intimacy and Sexuality While Living with Cancer are Normal

Sexuality and intimacy are important aspects of the quality of your life and cancer may cause dramatic changes to sexuality, sexual functioning, relationships, and your sense of self.

A cancer diagnosis does not necessarily mean you will lose interest in sex. Cancer does not automatically stop sexual feelings any more than it automatically stops hunger and thirst.

It is important to express your feelings and concerns to your healthcare providers. It is normal to have questions and concerns about intimacy. Many people have questions about their sex life during and after treatment, but only a few get the help they need. In a recent study with women who had breast or gynecologic cancers, only 7% asked for advice or medical help for sexuality problems. Yet 42% cared about sexuality problems and wanted help.

Ways to Maintain Intimacy with Your Partner

After treatment, some couples report more intimacy, an increase in physical closeness (without sexual intercourse), more appreciation of their spouse, and a stronger relationship.

Intimacy does not have to mean sex; it can mean:

- spending quality time together
- feeling closer (physically and emotionally) to one another
- feeling loved by your partner

Try to look at this as an opportunity to try new things and find out how you and your partner can find pleasure and intimacy together.

Tips to Increase Intimacy

- ✓ Give and receive good, long hugs every day.
- ✓ Hold hands.
- ✓ Give each other massages.
- ✓ Spend quality alone time together and talk about things beside cancer.
- ✓ Have open, honest discussions about both of your concerns.
- ✓ If you are embarrassed about showing a body part or scar, find new ways to cover them up. Try different positions that make you more comfortable.

Additional Resources

Roswell Park: Refer to your Taking the Lead book for tips on how to stay well and manage side effects during drug therapy. See Resources and Support on the next page.

National/International Resources

- Oncolink: www.oncolink.org Choose “Patients” and then “Support”
 - Women’s Guide to Sexuality During & After Cancer Treatment
 - [Men’s Guide to Sexuality During & After Cancer Treatment](#)
- American Cancer Society (ACS) cancer.org
 - Cancer, Sex, and the Female Body
 - Questions Woman Have About Cancer, Sex, and Getting Professional Help
 - Cancer, Sex, and the Male Body
 - Questions Men Have About Cancer, Sex, and Getting Professional Help
- Canadian Cancer Society (CCS) www.cancer.ca
 - Sex and Intimacy

Resources and

Roswell Park offers services and programs that can help you and your loved ones through treatment and increase your overall sense of well-being.

- **Multiple Myeloma Support Group**

When: 4th Wednesday of every month 6 p.m. - 7:30 p.m.

Location: Roswell Park Comprehensive Cancer Center, Jacobs Family Conference Room, Main Hospital, 1st Floor. For more information, or to attend, please contact: Jacqueline.Henry@RoswellPark.org [716-845-1300](tel:716-845-1300) ext. 1642 or email RoswellPark@IMFsupport.org.

- **11 Day Power Play Cancer Resource Center: 716-845-8659, option 1**

The Resource Center provides a warm, welcoming staff that offers a caring and personalized experience for patients and loved ones. The center provides general cancer information from Roswell Park clinicians and national patient and professional cancer organizations, online computers and printers, a DVD lending library, and a complimentary wig program. The Center is located on the 1st floor of the hospital, by the tower elevators. Hours: Mon-Fri, 9 a.m. – 4 p.m.

- **Department of Supportive Care**

The **Supportive and Palliative** care team provides supportive care at any time after diagnosis, including patients with advanced disease who are continuing treatment. Treatment focuses on controlling symptoms and managing pain. Services include psychological and spiritual support.

- **Supportive and Palliative Care: 716-845-8214** (or ask your doctor for a referral)
- **Department of Social Work: 716-845-8022** – Assistance with translation services, transportation, accommodations. Consultations and services are free and confidential.
- **Psychology Department: 716-845-3700**
- **Pastoral Care – Spiritual Support: 716-845-8051**
- **Cancer Pain Management:** Ask your doctor for a referral

- **Nutrition and Registered Dietitian Services**

Roswell Park's clinical dietitians are Registered Dietitians (RD) and can help if you are dealing with nutrition issues due to your cancer or treatment. Please ask your doctor/nurse for a referral.

- **Roswell Park's Online Community** www.cancerconnect.com/roswellpark

The community is a safe place where members discuss experiences and concerns and support one another. All you need is an email address.

- **Tobacco Treatment Services: 716-845-1300 Ext 7851**

Email: treattobacco@roswellpark.org Website: www.roswellpark.org/treattobacco

Smoke-free cancer patients feel better during and after treatment and have a better chance of recovery. If you are a tobacco user, whether you are ready to quit or just thinking about it, we can help. Our Tobacco Treatment Specialists will create a treatment plan tailored to you to help you increase your confidence and motivation to quit tobacco. We reach out to all patients who use tobacco, but you can also contact us.

The NYS Smokers Quitline also offers live telephone coaching, support materials, and social support at **1-866-NY-QUITS (1-866-697-8487)** and on their website: www.nysmokefree.com.

- **LegalCare at Roswell Park: 716-845-1300 Ext 6475; Email: LegalCare@RoswellPark.org.**

You may have a legal need if your health is interfering with your job or schooling; your insurance won't cover your participation in a clinical trial or has cut or stopped your benefits; you've recently lost a source of income; or you owe bills that you can no longer afford to pay. Current patients and their families are eligible for the first free, confidential legal consultation. Depending on the results, you may also qualify for free or discounted legal services.

- **Survivorship & Supportive Care Center: 716-845-4800**

The survivorship center offers comprehensive services for patients who have completed their active cancer treatment and are ready to move to a higher level of wellness as a cancer survivor. They help detect and manage complication or side effects from your disease or treatment and restore your body and soul with rehabilitative therapy, nutrition counseling, and emotional support and guidance.

These are some of the support services that are available to you and your caregivers. Please call **1-800-ROSWELL (1-800-767-9355)** or e-mail askroswell@roswellpark.org for information about Roswell Park and the services available here and in the community.

Notes

[illegible]

When to Call

Call us immediately if you have a fever of 100.4°F (38°C) or higher

Call us as soon as possible if you have:

- blood in your urine or stool or a persistent bloody nose
- severe nausea even though you took your prescribed medication
- pain or difficulty swallowing, urinating (peeing), or moving your bowels
- cancer-related pain even though you took your prescribed pain medication
- worsening dizziness, weakness, or fatigue
- any falls

Lymphoma/Myeloma Center: 716-845-1642. Hours: 8 a.m. – 5 p.m.

Roswell's main number: 716-845-2300 (Available 24/7)



The Lymphoma/Myeloma Center's Tips for Managing Drug Therapy - A Companion Guide to Taking the Lead

