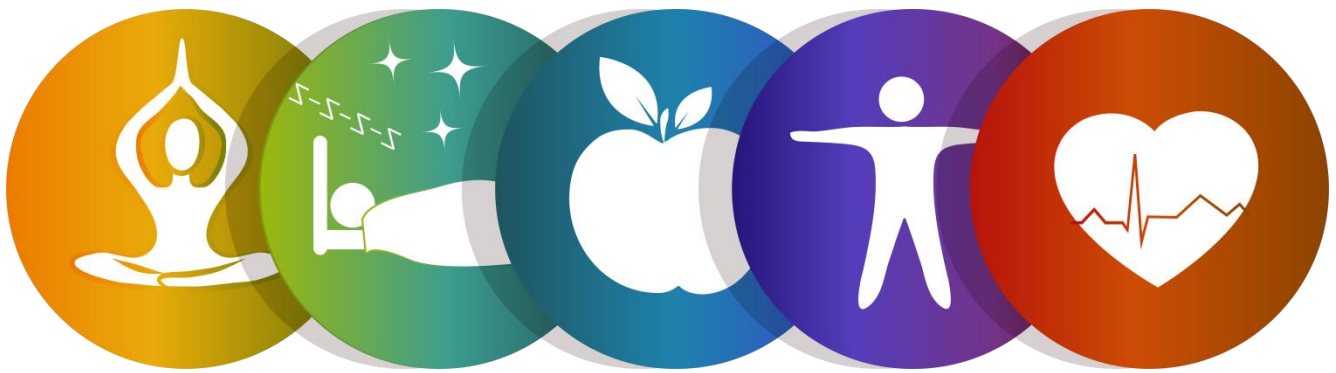


Taking the Lead



What You Can Do To Live Well
During Drug Therapy



**PATIENT
EDUCATION**

Important Phone Numbers

Call Your Center or 1-716-845-2300*

My Center/Doctor:

My Medical Record Number (MRN)

Roswell Park Locations

- **Downtown Buffalo Hospital** **716-845-2300***
 Toll Free **1-800-ROSWELL (1-800-767-9355)***
- Amherst Center (satellite) 716-845-2900
- Niagara Falls Center (satellite) 716-845-3500

*Both the 2300 number and the toll-free number are available 24/7.

Roswell Park Care Network

Breast Care of WNY	716-332-6834
Cayuga Medical Center Radiation Oncology (Ithaca)	607-274-4011
Ellis Medicine Oncology (Schenectady)	518-243-4762
Jamestown Medical Oncology & Hematology	716-664-1909
Niagara Falls Memorial Medical Center (Thoracic Oncology Surgery)	716-278-4597
Northtowns Hematology Oncology	716-634-3340
Niagara Hematology Oncology	716-298-4869
Oneida Health Cancer Care	315-361-2381
Oneida Health Roswell Park Oncology (Radiation Medicine)	315-361-2351
Southtowns Radiation Oncology	716-674-6800
Roswell Park Dermatology	716-845-1600
Roswell Park Urology – Niagara County	716-285-0853
Southtowns Hematology Oncology	716-674-3104
Upper Allegheny Health System	
• Barry St Health Center Medical Oncology & Hematology (Olean)	716-543-3255
• Bradford Regional Medical Center (Bradford PA)	814-362-8425
• Mildred Milliman Radiation Medicine Center (Olean)	716-373-7134
Walker Center for Cancer Care (Watertown)	315-785-4673



When to Call

Please note: Any of these symptoms may be urgent in a particular patient. Your doctors and nurses will tell you what symptoms you need to watch for. **If you have chest pain or trouble breathing, call 911 and go to the nearest emergency room.** Otherwise, follow these guidelines.

<p>Fever/ Signs of infection</p> <ul style="list-style-type: none"> ○ Temperature of 100.4° F (38°C) or higher ○ Chills/shaking/shivering ○ Sore throat ○ A break in the skin with redness around it or that is draining yellow or green liquid ○ Flu-like symptoms (achy, tired, headache) ○ Urination problems (pain, burning, going more/less than usual, red or cloudy urine, pain in back or belly, or no improvement after 3 days of taking UTI medication) ○ Redness, swelling, or pain along a vein <p>Important! If your white blood cell (WBC) count is very low, you must tell your provider if there is any change in how you feel because you may not get the usual symptoms of infection.</p>
<p>Signs of an allergic reaction: rash, hives, swelling or itching in mouth/tongue/face, fast heartbeat, wheezing, lightheadedness, diarrhea, nausea, vomiting</p>
<p>GI problems</p> <ul style="list-style-type: none"> ○ Mouth problems: white patches, open sores, or new or worsening mouth or tooth pain ○ Vomiting: 4-5 times in 24 hours, violent puking, vomiting after a painful or swollen belly ○ Constipation: More than 2 days since you normally would have had a bowel movement ○ Diarrhea: More than 4 episodes in 24 hours or a sudden, acute attack lasting more than 24 hours, or diarrhea with severe belly pain or cramping ○ Skin or whites of your eyes look yellow (jaundice)
<p>Signs of dehydration: intense thirst, dry skin/mucus membranes, tented skin (pinched skin stays in tent shape after you let go), dark urine, peeing less than 1 cup a day</p>
<p>Unusual bleeding or bruising, particularly if you take “blood thinning” medication like warfarin/ Coumadin®, apixaban/Eliquis®, enoxaparin /Lovenox®, or rivaroxaban /Xarelto®</p>
<p>Holding fluids: Swelling in feet, ankles, or elsewhere; blurry vision; suddenly gaining 2-3 pounds a day for 2 days in a row; stretched/shiny skin; pitting skin (press on skin, let go, indent remains)</p>
<p>Skin problems/rash: new rash; rash that is getting worse; rash that blisters, peels, or causes an open wound; or a rash that affects the any mucus membrane (mouth, lips, nose, eyes, vagina, etc.)</p>
<p>Any symptom that stops you from drinking or eating</p>
<p>Shortness of breath with little/no activity, new or persistent cough, need increased home oxygen</p>
<p>Symptoms of Peripheral Neuropathy (PN): numbness, burning, or tingling in your hands or feet; extreme sensitivity to touch; feeling like you are wearing gloves or socks when you are not; clumsiness; muscle weakness; trouble touching cold items; existing PN is getting worse</p>
<p>Fatigue that lasts weeks; causes confusion, stress, or sadness; makes it hard to get through the day, or keeps you in bed for more than 24 hours</p>



Inside Cover: Important Phone Numbers
When to Call

Introduction 5

Promoting Wellness

- Managing Daily Life 6
- Good Nutrition 8
- Activity & Exercise 10
- Sleep 12
- Mouth & Dental Care 14
- Relaxation & Stress Management 16
 - Relaxation Techniques 18
- Body Image & Hair Loss 20
- Sexuality & Fertility 22
- Preventing Infection 24
- Precautions at Home 26

Managing Side Effects

- Fever 28
- Fatigue 30
- Taste Changes 32
- Loss of Appetite 34
- Nausea & Vomiting 36
- Diarrhea & Dehydration 38
- Constipation 40
- Skin & Nail Changes 42
- Peripheral Neuropathy 44
- Bladder Health & Urinary Problems 46
- Chemobrain – memory/concentration 48
- Medical Marijuana in NYS 50
- Support and Resources 52
- Think About Your Life 55
- Pharmacy Services 59

Introduction

Welcome to Roswell Park's Drug Therapy program. The thought of starting cancer treatment often causes anxiety and raises questions. This booklet provides tips on how you can become an active partner in your care and:

- strengthen your immune system
- lessen the impact of treatment on your daily life
- minimize side effects


It also explains what you should tell your doctor, and when.

Brochures on managing specific side effects are available in our Chemotherapy and Infusion Centers, the Resource Center for Patients & Families (Inside the Sunflower Café/cafeteria on the first floor of the main hospital), and in the health library on the Roswell Park patient portal.

There is a lot you can do on your own but remember that 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.

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



Managing Daily Life

Key Points

- ☀️ **Wash your hands!** Treatment can weaken your immune system and raise your risk of infection.
- ☀️ People have different reactions to drug therapy. Talk to your doctor or nurse and take some time to figure out what activities you can do during treatment and which will require help.
- ☀️ Evidence shows that smokers don't tolerate treatment as well as nonsmokers. It can worsen side effects and slow down healing.

Avoiding Infections

There may be times during treatment when you have a higher risk of infection and need to take extra precautions to protect yourself and others. Some survivors shared tips on how they were able to safely continue their daily activities.

- ✓ Avoid people who have colds or other contagious illness. During flu season, avoid dense crowds in confined spaces. Choose to sit in an area with fewer people.
- ✓ Shop early in the day or late at night, when the crowds are smaller.
- ✓ Ask your doctor if you should buy a package of clear gloves like food workers wear. They are very inexpensive can be useful, especially during cold and flu season.
- ✓ If your blood cell counts are low, you may want to shop online or have groceries delivered.
- ✓ Tell your doctor if you have pets and ask how you can stay safe around them. If you are at a high risk of infection, don't pick up dog waste or clean litter boxes, bird cages, and fish tanks. Wash your hands after touching any animals.

Day to Day

- ✓ If you feel well enough, continue your routines. With your doctor's OK, you may still be able to work, spend time with family/friends, and participate in hobbies and outings.
- ✓ Give yourself some time to adjust to your diagnosis and all the new thoughts and feelings. You may find yourself putting on a cheerful front when you don't feel cheerful. Sometimes that may be helpful but don't avoid your disturbing feelings altogether or you may feel worse instead of better.
- ✓ Ask yourself how you want to spend your time. Who do I like to be with? Who makes me laugh or feel happy? What are my passions? What types of things do I enjoy the most and least?

Fun

Try to do something just for fun, not because you have to do it. Be careful not to tire yourself out. Cancer treatment can cause fatigue of its own, and some people get depressed when they are too tired. Focus on getting enough rest, making healthy food choices, and staying active so you can enjoy your activities.

Babies and Children



- You do not usually pose a risk to children while on drug therapy. The exception may be in the 2-3 days after treatment, when the drug may still be in your body fluids such as urine, stool, and vomit. During this time, take a few precautions. Use a separate bathroom if you can. If not, flush the toilet twice after you use it, and wipe off the seat. Always wash your hands after using the bathroom.
- If you are caring for children, you may be at greater risk for infection. A virus that may only give a child a runny nose could make you sick. It's best to stay away from children (and adults) who are visibly sick or have recently had a vaccine that contains a live virus. (measles, chickenpox, polio).
- Depending on your drug regimen, your doctor may ask you to wear a mask if you must be around a sick child.
- Wear gloves when changing diapers. Throw away the gloves when done and wash your hands.
- Most drugs carry a warning not to breastfeed while using them.

Alcohol

- Whether or not you can have alcohol during treatment will depend on the drugs you receive.
- Alcohol may interfere with how well they work, or it may increase the risk of side effects - or make them worse.
- Ask your doctor or clinical pharmacist if it is safe for you to have alcohol.
- Discuss any difficulties you have, or have had, with alcohol.
- If your sense of taste changes, alcohol may not taste as good as it did before. This usually goes away when treatment is over. **Do not drink alcohol if you have mouth or throat sores.**

Tobacco Products

- Evidence shows smokers do not tolerate drug therapy (or radiation therapy) as well as nonsmokers. In some cancers, studies suggest that the outcomes are better for those who quit smoking when they are diagnosed with cancer.
- Smoking can worsen side effects like mouth sores and changes in taste, which in turn can decrease your ability to eat and affect your nutritional status.
- We understand that quitting can be quite difficult. Roswell Park has support services that can help. People who quit smoking often report that they have more energy almost immediately.



Good Nutrition

Key Points

- Research shows colorful, whole foods rich in vitamins, minerals, and fiber are preferable to dietary supplements.
- If you are not sure about the safety of a food in your refrigerator, don't take the risk.
- Drink 2-3 quarts a day – water is best.

Healthy food choices are very important during treatment. You need a certain amount of calories, protein, vitamins, and minerals daily to help you head and lessen side effects.

- ✓ **Choose foods and beverages that you can tolerate best.**
- ✓ **Aim for choices rich in healthy nutrients to give you the energy to recover, the nutrients to heal, and the calories to prevent unintended weight loss.**

This is not always easy. Side effects may make it hard to eat a variety of healthy foods. As a result, you may lose weight and muscle mass.

The Registered Dietitian Nutritionists (RDNs) at Roswell Park are part of your health care team. They are available to help you manage nutrition-related side effects and improve your general nutrition health before, during, and after treatment. Ask your doctor or nurse for a referral to meet with an RDN.

Food is a Better Choice

Research shows colorful, whole foods rich in vitamins, minerals, and fiber are better than dietary supplements. Why?

- Dietary and herbal supplements don't provide the full range of healthy nutrients you can get in whole foods. Plant foods have unique combinations of healthy fibers, vitamins, minerals, and phytochemicals that cannot be duplicated in a supplement.
- Some dietary supplements, even those available over-the-counter, have the potential to interfere with cancer treatments.
- Supplements are often made with levels of nutrient far above the daily recommended dose, which can be harmful – especially when you are receiving cancer treatment. It is much harder to get too much of any nutrient from eating foods.
- Eating a variety of healthy foods is the safer choice.

Recommendations for Healthy Food Choices

- When you are feeling well, and your physician has not restricted your diet, focus on making food and drink choices that are in line with the current Dietary Guidelines for Americans.
- The number of servings for each food group will vary based on your individual energy needs.
- The general ranges of servings **per day** for most adults (based on a 1600-2200 calorie diet) are:
 - 2-3 cups of vegetables
 - 1-2 cups of fruit
 - 5-7 servings of grain-based foods (at least half should be whole grain)
 - 2-3 servings of dairy foods (fat-free or low-fat milk, yogurt, cheese)
 - 3-4 servings of protein foods (lean meat and poultry, seafood, eggs, nuts, legumes such as beans, peas, and lentils)
 - 40-65 grams of fat (use oils instead of solid fats)
 - Low sodium food choices
 - Water instead of sugary drinks. Drink 2-3 quarts/liter of water a day, if possible

Promoting Good Nutrition

- If you are losing weight or if you are having trouble eating a full, healthy diet, you can increase calories, protein, vitamins, and minerals, with nourishing snacks or liquid supplements, such as Carnation Instant Breakfast®, Boost® or Ensure® between or with meals.
- If you've lost your appetite, use fortified milk powder or whey protein when you make puddings, creamed sauces, mashed potatoes, and breakfast batters.

Practice Food Safety

Your immune system may be weakened from treatment. Practice food safety every day.

- ✓ Keep fruits and vegetables in the refrigerator.
- ✓ Be sure to **thoroughly wash** all your fresh fruits and vegetables, including the skins of melons.
- ✓ Do not cross-contaminate. Use different knives and cutting boards for your meat and vegetables.
- ✓ Thaw your meat in the refrigerator instead of the countertop.
- ✓ Do not eat raw or undercooked meat, fish, poultry, or eggs (including raw cookie dough).



If you are not sure about the safety of a food in your refrigerator, don't take the risk.

WHEN IN DOUBT, THROW IT OUT!

The booklet, *Food Safety for Cancer Patients* is available in the Resource Center for Patients & Families (1st floor of the hospital, inside the cafeteria) and on the Federal Food Safety website: [foodsafety.gov](https://www.foodsafety.gov). This website also offers a FoodKeeper app with information on the proper way to store foods and beverages.



Activity and Exercise

Key Points

- There are many benefits to remaining active during treatment including less fatigue, faster recovery, and a greater feeling of well-being.
- Always check with your doctor before beginning any activity or exercise program.
- Look for programs designed for cancer patients, like LiveStrong® at the YMCA program.

Being physically active during cancer treatment may bring great benefits.

- More energy and less fatigue
- Greater feeling of well-being and less stress and anxiety
- Faster healing and recovery
- Increased stamina and strength and better muscle tone
- Lower risk of constipation
- Improved body image
- A clearer mind

Tips on Choosing Your Activity Level/Exercise

Your ability to exercise will depend on the type and stage of your cancer, your treatment, and your physical condition. **Your activity level should be based on what's safe and what works best for you.** Take your physical restrictions into account and choose activities that you like.

Goal: Stay as active and healthy as possible during treatment.

Goal: 30+ minutes of aerobic exercise 5 days a week.

Ready, Set, Go

- ✓ **Always check with your doctor before starting any exercise program**, particularly if your treatment can affect your lungs or heart, the organs that put oxygen in your blood and pump the blood through your body. Be sure you understand what you can and can't do.
- ✓ **Start before you begin treatment, particularly if you have been inactive for a while.** Ask your doctor for a referral to our outpatient Rehabilitation Center for help in setting up your plan. For example, exercises can be prescribed to improve the range of motion and prevent lymphedema in women who have lymph nodes removed during breast surgery.
- ✓ **If you exercised before treatment**, you may need to take it slower. This may mean exercising less often, for a shorter amount of time, at a lower intensity or doing easier exercises.

- ✓ **If you were inactive before treatment**, start with low impact activity, like walking, for a short period of time – 5 to 10 minutes a day. When you feel strong enough, you can slowly build up to 30 minutes or more. Let your doctors and nurses know if you have pain when you increase your activity.
- ✓ There are some exercises you can do even if you must stay in bed.
- ✓ Even if you have never done physical activities before, you can start now. Get your doctor's OK before you start or add any new exercise or activity.



Precautions for Exercise During and Shortly After Cancer Treatment

- ✓ **Always check with your doctor before starting a new activity or doing strenuous activity.**
- ✓ **Drink 2-3 quarts a day of water a day** unless your doctor tells you to limit fluids.
- ✓ **Moderate exercise is recommended. Try a brisk walk.**
- ✓ Warm up before (march in place and/or move your arms) and cool down afterwards.
- ✓ Stretching can help prevent sore muscles and ease tension, stress, and back pain.
- ✓ To help increase feelings of well-being and increase flexibility and balance, try gentle stretching, movement, and meditation exercises like tai chi or yoga.
- ✓ If the doctor gives you the OK to clean the house or work in the garden, they count as exercise!
- ✓ Look for programs designed for cancer patients, like the LiveStrong® program at the YMCA.
- ✓ When you have bloodwork done, ask your doctor for the results and whether you need to change or stop your exercise routine.
- ✓ If you are too tired for your normal exercises: Try doing 10 minutes of light exercise.

Special Circumstances

- Low white blood cell count (leukopenia, neutropenia): Avoid fitness centers and sick people.
- Fever, pain, nausea, a low red blood cell count (anemia), or low electrolytes (sodium, potassium, etc.): **Don't exercise.** You may have low electrolytes if you have had a lot of vomiting or diarrhea.
- If you have a catheter or feeding tube: Avoid activities that increase your risk of infection (ocean, lake, and pool water) or that tug on the muscles near your catheter or tube. Talk to your doctor about activities that are safe for you.
- If you are having radiation: Do not expose the skin in the radiated area to chlorine (pool water).
- If you have osteoporosis (thinning bones), cancer in your bones, nerve damage, poor vision, or weakness: Don't do exercises that put a lot stress on your bones, like using heavy weights.
- If you have numbness in your feet or balance problems: You are at higher risk of falling. Try to stick with activities that lessen your risk – use a stationary bicycle instead of a riding on the street, don't do weight bearing or weight lifting activities, and stay away from uneven surfaces like broken or slanted sidewalks.



Sleep Problems

Key Points

- Healthy sleep – you fall asleep in 15-20 minutes and wake up feeling rested.
- Keeping a sleep schedule (going to bed and getting up at the same time each day) may help.
- Turn off all screens (TVs, phones, tablets) at least 1 hour before you go to bed.
- Poor quality, or not enough, sleep affects your immune system, which raises your risk of infection. It can also affect your memory, concentration, mood, and relationships.

Despite battling fatigue, you may find yourself having sleep problems. Maybe you are having trouble falling asleep or staying asleep. Or perhaps you just don't feel rested when you wake up.

Sleep needs and patterns differ among people even under the best of circumstances. For example, a nap makes some people feel reenergized but makes others feel sluggish or cranky.

Signs You are Getting “Healthy” Sleep (National Sleep Foundation)

- You fall asleep within 15-20 minutes of lying down to sleep.
- You usually sleep a total of 7-9 hours in a 24-hour day.
- While in bed, your sleep is continuous—you don't have long periods of lying awake.
- You wake up feeling refreshed and alert and can be productive while awake. (It's OK if you have periods when you are less alert... as long as your alertness returns.)
- Your partner or family members don't notice any disturbing or unusual behavior from you while you sleep (snoring, pauses in breathing, restlessness, or other nighttime behaviors).



The Cost of Poor Sleep

- Extra stress on your immune system, which means a higher risk of infection
- Mood swings
- Problems with memory, concentration, and decision making
- Problems with daily activities and healthy relationships

Tips for Healthy Sleep

- ✓ Do not have any caffeine, chocolate, nicotine, and alcohol in the evening.
- ✓ Turn off the TV and computer at least 1 hour before going to bed.
- ✓ If you find it hard to turn your brain off, make a list of things you have to do the next day.
- ✓ Make a routine to help your body and mind relax and get ready for sleep. Try taking a bath, listening to music, or drinking a glass of milk.
- ✓ Keep a regular sleep schedule 7 days a week. Go to bed and wake up at the same time every day.
- ✓ Use the bedroom for sleep and intimacy only, not as extra living and work space.
- ✓ If you feel pressured by watching the clock, turn it around.
- ✓ If it's OK with your doctor, try some mild - moderate exercise during the day, such as taking a 20 minute walk most days. Exercise will help keep you up during the day, lessen stress, improve your mood, and may also help with sleep problems.
- ✓ If you don't fall asleep after 15 minutes go to another room. Avoid stimulating activities.

Tips to Manage Insomnia

- ✓ Try to identify the cause of your sleep problems. Pain? Depression? Worry? Too much caffeine?
- ✓ Share your thoughts with your health care provider about your sleep problems. One way is to keep a sleep diary. Chart the times you are asleep and awake. Write down what you think may be adding to your sleep problems.
- ✓ Do not eat or exercise within 2 hours of bedtime.
- ✓ Make the room dark. Turn clocks with illuminated faces away from you.
- ✓ Try not to nap during the day. If you must take a nap, only sleep for 1 hour or less.
- ✓ Try relaxing music or an activity that helps you feel less tense - singing, cooking, painting, reading, praying, etc.
- ✓ If you have a lot of caffeine, try to slowly lower the amount (and none in the evening).
- ✓ If you can't sleep because of pain, make sure you are taking your medication exactly as prescribed. If this is not helping your pain, talk with your health care provider.
- ✓ If your sleep problems are because you are worried or anxious about your cancer, talk with your health care provider or social worker, or join a support group or Roswell's online community. community.roswellpark.org
- ✓ If you are feeling depressed and have lost interest in activities you used to enjoy, feel hopeless, or don't want to get out of bed/chair, tell your health care provider.
- ✓ Some people have found over-the-counter remedies helpful such as melatonin products. **Always check with your health care provider before taking any medications – even over the counter medications.** Some sleep aids contain ibuprofen or acetaminophen (Tylenol®) and may not be right for you because they can hide a fever, an important warning sign of infection.
- ✓ Ask your doctor or nurse if you are taking your medications at the right times of the day. For example, it is best not to take steroids in the evening.



Mouth and Dental Care

Key Points

- ☀ Drug therapy can cause dry mouth (xerostomia) and mouth/throat irritation or sores.
- ☀ Do not smoke, use tobacco products, or drink alcohol – all can cause mouth problems. Do not use mouthwash that contains alcohol.
- ☀ If you have a dry mouth, try artificial saliva and sugarless candy/gum. Avoid very salty and very sweet foods.

While you are in treatment, your mouth may be dry, tender, irritated, and more likely to get sores or infection. You may be more sensitive to hot or cold foods, have changes in your sense of taste, or have a bad or metallic taste in your mouth.

Prevention Tips

- ✓ Get a dental check-up before you begin treatment. Talk to your doctor about how often you should have dental check-ups. Ask your dentist about fluoride treatments.
- ✓ Keep your mouth as clean and moist as possible. A dry mouth, called xerostomia, increases your risk of infection and tooth decay, and it is uncomfortable.
- ✓ Lips: Use a moisturizer or balm that is water soluble (dissolves in water). Avoid products that contain glycerin or petroleum jelly (Vaseline®) - they will dry out your lips.
- ✓ Dentures: Clean them twice a day. If they feel loose, call your dentist to have them refit.
- ✓ Do not smoke, use tobacco products, or drink alcohol – all are hard on tissues in your mouth.
- ✓ Regularly check your mouth and look for sores or white patches.
- ✓ Avoid acidic, spicy, and hot foods. **Did you know that carbonated beverages are acidic?**
- ✓ Drink lots of water 2-3 quarts (4 cups = 1 quart) every day, unless your doctor tells you to limit your fluids. Keep a water bottle with you to remind you to drink.

How to Take Care of Your Mouth

After meals and at bedtime:

- ✓ **Brush** with a soft toothbrush (run your brush under warm water to make it softer) and a nonabrasive fluoride toothpaste.
- ✓ **Rinse** your mouth for 30-60 seconds with either a baking soda rinse or a fluoride mouthwash. **Do not use mouthwashes or rinses that contain alcohol.** They can cause dry mouth and irritation. Rinse at least 4 times a day – more often if your mouth is sore or you have thick mucus.
- ✓ **Floss** gently with unwaxed floss unless your doctor or nurse tells you not to floss. (If your platelet count gets too low, you may be asked to stop flossing for a short time.)

Baking Soda Rinse

½ teaspoon of baking soda mixed in 8 ounces of warm water

Tips for Dry Mouth

- ✓ Increase your baking soda mouth rinses to every 2 hours while you are awake.
- ✓ Try a few dry mouth products to see what works for you. Examples: Biotene® Dry Mouth Oral Rinse, Lubricity™ Dry Mouth Spray, Xylimelts® (xylitol product), and Oralbalance® gel. **Avoid all mouthwashes that contain alcohol or hydrogen peroxide.**
- ✓ Use artificial saliva (also called saliva substitutes). You'll find it with other mouth care products.
- ✓ Suck on sugarless hard candies or chew sugarless gum.
- ✓ Try acupuncture.
- ✓ Avoid foods that have a high salt or sugar content.

If you snore or breathe through your mouth, you are more likely to have a dry mouth.

Tips for Mouth Sores or Discomfort

- ✓ Increase your use of the baking soda rinse to every 2 hours while you are awake.
- ✓ Do not eat or drink citrus or spicy foods and liquids.
- ✓ Use a straw. (May allow you to drink with less discomfort)
- ✓ Remove dentures or partial plates and leave them out as much as you can. Soak them in cleaning solution for 8 hours. If they're getting loose, let your dentist know you need them refitted.
- ✓ If you are using gels to help with mouth pain, know they may make it difficult to swallow and raise the risk of choking.
- ✓ Do not use glycerin or lemon glycerin swabs. They dry out your mouth.
- ✓ Take pain medicine before you eat.



Relaxation and Stress Management

Key Points

- Fear of the unknown and uncertainty about the future creates stress. Learning about your illness and treatment plan is the first step to understanding what you are facing.
- Use relaxation techniques (deep breathing, visualization) before and during a stressful situation.
- Don't be afraid to ask for help, it is a way of taking control and recognizing you cannot do everything. Let friends and family help.

It is common to have negative thoughts and feel anxious about a cancer diagnosis. You may feel overwhelmed by information and decision-making. Signs that your stress level may be getting the best of you include tense muscles (neck and back aches), headaches, fatigue, indigestion, racing thoughts, loss of appetite, and sleep problems. Here are some tips to help relieve tension.

- Fear of the unknown and uncertainty about the future creates stress. Learning about your illness and treatment plan is the first step to understanding what you are facing.
- Keep a notebook of your concerns and questions to bring to your doctor visits. **Before you go online looking for answers, remember that only your doctors can give you detailed information about you and your cancer.**
- Think about what has helped you to cope in difficult situations in the past. Could it be helpful now? If you find something isn't working for you, try something else.

Planning for Drug Therapy

Mind and Attitude: Prepare your mind as well as your body. Practice training your mind to focus on health and recovery, not on illness and death.

Tips from Patients on Coping with Drug Therapy

"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 your iPod, 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."

Emotional support: Look for a supportive group where you can express your fears and anxiety. While family and friends can be an important source of support, there may be some things you feel you can't talk about because it upsets them. Roswell Park offers in-person support groups and an online community. community.roswellpark.org

Physical: Get to know your body's normal reactions so you can recognize when you are tense. Shallow breathing and a fast pulse are often your body's reaction to stress. Be aware of your needs.

- ✓ Rest when you are tired.
- ✓ Limit tea and coffee.
- ✓ Drink water regularly throughout the day.
- ✓ Eat nutritious food.
- ✓ **Be kind to yourself.**

Tips on Reducing Stress

- ✓ Take a friend along to support you during treatment.
- ✓ Use relaxation techniques like deep breathing or visualization before and during a stressful situation.
- ✓ Have a relaxing massage or reflexology treatment once a week. Check with your doctor first.
- ✓ Learn to relax. Deep breathing helps you relax. Try to take several deep breaths each hour.
- ✓ Communicate. Talking to other people can help you deal with your problems.
- ✓ Adequate exercise will help you to reduce tension. Even a gentle walk can loosen you up. Check with your doctor about when you can start to exercise, and type of exercise is best for you.
- ✓ Laugh! You will be surprised how good it can make you feel.
- ✓ Have fun and learn to play a little. Keep up your hobbies and try to have regular outings.
- ✓ Listen to relaxing music in peaceful surroundings. (Hang a 'Do Not Disturb' sign!)
- ✓ If you have strong religious/spiritual beliefs, try going to your spiritual leader or counselor.
- ✓ Make lists. Make a list to help of what you want to do. If you don't get them all done put them on the list for next time.
- ✓ Take control of your life. Live up to your expectations not someone else's. Say "no" when extra commitments will cause stress.
- ✓ Don't be afraid to ask for help. It is a way of taking control and recognizing you cannot do everything. Let friends and family help.

Relaxation Techniques

Relaxation techniques can help you:

- calm your mind
- sharpen your focus
- manage anxiety, pain, and other physical symptoms
- relax
- keep a clear head for making treatment decisions

Some people find these simple techniques greatly improve their quality of life.

A Simple Relaxation Technique

A simple technique like this can help your body relax and avoid a buildup of tension. Before you start, put your phone on mute and leave a note on the door so that you are not disturbed.

- Lie, sit, or stand with your feet apart. Rest your hands loosely in your lap or by your side.
- Close your eyes and slow yourself down for a few minutes by breathing a little deeper and slower than usual.
 - Be aware of how your whole body is feeling through your toes, feet, calves, thighs, abdomen, chest, back, fingers, arms, shoulders, neck, head, scalp, and face.
 - Each time you breathe out, focus on a different area of your body. If there is any tension there, let it go.
 - Let all your muscles slowly relax and enjoy the peaceful, calm feeling of total relaxation.
 - Rest quietly for a while and relax your mind by thinking about the pleasant experience of complete relaxation.
 - Open your eyes, stretch slowly, and return to your day.
- Allow yourself a regular period of relaxation. Ten to 15 minutes, twice a day, may be enough. You might like to record instructions with some relaxing music.

Meditation

The word *meditation* is a general term for different ways to raise self-awareness, relax, and bring inner peace. Repeating a word or sound (mantra) is one form of meditation. Choose a word that is important to you. 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 where there are no distractions. With practice, you can meditate anywhere, at any time.

Deep-Breathing

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

1. Take in a deep breath.
2. Hold the breath for several seconds.
3. Exhale slowly.
4. Repeat 1-2 more times.

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 anxiety or pain 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 you trust.
- Join a support group, the online Roswell Community, or a “buddy” program – you do not have to face this alone!

It may take time and practice to reach the point where you can use these techniques successfully in high stress situations. Beginners should practice when your stress level is low or moderate. If you become frustrated during a session, stop, and try again later. With regular practice, you can learn to use the power of your mind to decrease anxiety, lessen discomfort, and increase your sense of well-being.

Roswell Resource: For help in coping with anxiety, fear, or depression, or dealing with the life changes caused by your illness, please contact the Social Work Department at **716-845-8022**, or request a referral to meet with a Roswell Park psychologist from a member of your health care team.



Body and Self-Image

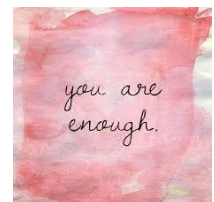
Key Points

- Stay as active as you can. It helps you keep a positive outlook.
- Physical changes such as hair loss and weight changes may be temporary or permanent. Preparing yourself can help you cope with the changes.
- Not all chemo causes hair loss. Ask your doctor/pharmacist about your treatment regimen.

- Cancer and its treatment can change how your body looks, feels, and works.
- Physical changes may affect how you think and feel about your body, your appearance, and yourself. For some, those feelings mean becoming self-conscious, embarrassed, or ashamed. For others, it challenges their view of who they are.
- Physical changes such as hair loss and weight changes may be temporary or permanent. Either way, you will have to figure out how to cope with them. Preparing yourself can help change the way you look at yourself.
- Understand that it is okay to be upset about changes in your body but also know that accepting those feelings is part of the healing process.

What Can You Do?

- Try to be physically active. Physical activity has been linked to lower rates of depression among cancer survivors. Talk to your doctor about what activities are right for you and see the section, *Activity & Exercise*.
- Talk to your health care provider about your mental health before, during, and after treatment.
- Keep track of your anxiety, depression, and other concerns.
- Visit the Roswell Park Resource Center for information and support to guide you through your journey. There is a complimentary wig program, a Cancer Coach program (pairs up a patient who is newly diagnosed or in treatment with a survivor for emotional and practical support), and patient education materials that cover cancer, procedures, resources, and support services.
- When the initial shock of diagnosis is behind you and you've found a rhythm in your treatment, you may begin to reflect on how your body has changed and how you feel about it. You may begin to change the way you see yourself and start building towards your 'new normal'. Though this is a positive process overall, it may involve some grief over what has changed – and that is normal.
- Understand that the way you look and feel is temporary, regardless of sickness or health. Anyone's appearance can change for a period of time for whatever reason.



- Although the changes brought by cancer may sometimes bring feelings of fear, anger, and frustration, many people say they have had positive feelings as well, including:
 - appreciation for the strength of their bodies
 - feelings of gratitude and peacefulness
 - appreciation that life is meaningful
 - new relationships with caregivers and other patients
 - a change in priorities and new perspectives about meaning in life and their goals

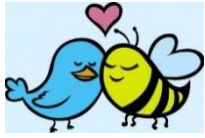


Hair Loss

- You may be surprised by your strong reaction to losing your hair. Perhaps it made cancer real for the first time, or you just weren't prepared for how you look.
- Not all drug therapies cause hair loss. Combination drug regimens that include doxorubicin, docetaxel, paclitaxel, or etoposide are more likely to cause hair loss than single drug therapies.
- High-dose, intravenous (IV) chemo is more likely to cause total hair loss than low-dose or oral drug therapy. Total hair loss includes eyelashes, eyebrows, and hair in the nose, armpit, and pubic area.
- The extent of hair loss may depend on a number of factors: the drug being used, the dose, how it is given, and how frequently it is given.
- Hair loss may begin 2-3 weeks after your first treatment, or it may not begin until after your second cycle.
- Hair loss can be fast or slow, partial, or complete, and hair may fall out in clumps or just thin out.
- Hair may start growing back during treatment or 3-6 months after treatment ends.

What Can You Do?

- ✓ Be proactive and learn all you can ahead of time.
- ✓ Ask your doctor or nurse if your drug therapy causes hair thinning or loss, when you can expect it to begin, and if they expect it to grow back after treatment ends.
- ✓ if you've been told to expect hair loss:
 - Cut your hair short or shave your head.
 - Hats, scarves, and caps may help you feel better about your appearance while preventing heat loss and protecting your scalp from the sun.
 - Get a wig or other head covering. The Resource Center for Patients and Families offers cancer patients one wig and one head covering per year at no cost. Wig stylists are available once or twice a week. You can make an appointment to get your wig styled. The Resource Center is on the first floor of the hospital, in the cafeteria. It is open Mon.-Fri., 9 a.m.-4 p.m. The phone number is **716-845-8659**.



Sexuality and Fertility

Key Points

- If you may want a family in the future, speak with your doctor before drug therapy begins.
- Treatment *may* affect your sexual desire, but it varies from person to person.
- Intimacy does not always mean sex. Many couples have found new ways of intimacy, appreciate their partner more, and reported a stronger relationship.
- Do not get pregnant, father a child, or have unprotected sex during treatment and for a few months afterwards. Barrier methods of birth control (condom, diaphragm) are recommended.

Cancer and/or drug therapy can affect your sexuality by causing changes in your sexual function, sexual desire (libido), or your ability to continue the sex life you had before your diagnosis. Even if sexuality has been an important part of your life up to now, you or your partner may feel differently.

While sexuality can do wonders for your self-image, your body, and your relationships, remember that your treatment can change things, and you may have to try something new. Here are some suggestions from others who maintained or improved the intimacy in their relationship during drug therapy.

- A cancer diagnosis and treatment does not necessarily mean you will lose interest in sex, but you might. It is important to be honest with your partner.
- You or your partner may think that sex shouldn't matter or be desired while you fight cancer. But sex, and the loving and caring that go with it, can be life-affirming.
- Sexual desire can range from being not at all interested to having a very active desire for sex. It varies from person to person and over time.
- Stress, fatigue, pain, hormonal changes, and nausea can lower sexual desire.
- Try to look at this as a chance to try new things and find out how you and your partner can find pleasure and intimacy together.
- It may help if the intimate partner who does not have cancer also tells the healthcare provider about their sexuality and intimacy concerns.
- Some couples report more intimacy, an increase in physical closeness (without sexual intercourse), more appreciation of their spouse, and a stronger relationship.
- You may not be interested in sex. It is also common for people to have problems with sex during cancer treatment. Until your treatment has ended and you feel better, you and your partner may need to find new ways to be intimate. This can mean spending quality time together, feeling closer (physically and emotionally) to one another, feeling loved by your partner; and caressing, kissing, and touching.



- You cannot get cancer from kissing, touching, or having sex with someone who has cancer. Sex does not cause cancer to grow faster and it does not increase the chance that cancer will return.
- Though it may be uncomfortable to start a conversation about sexuality with your doctor or nurse, it will be worth it if you learn about ways to improve your relationship and lessen stress.
- Remind your partner how much you love and appreciate him or her.
- Take your time—appreciate and enjoy each other and the gift of being able to be fully open and intimate with one another.
- Set the mood – try lighting candles and playing music.

Coping with Physical Changes

- ✓ Take a warm shower or bath to help relax your body.
- ✓ Take a nap before intercourse to help you feel less tired.
- ✓ If you need to take medication to prevent nausea or pain, take it 30 to 60 minutes before sexual activity. Note that some of these medications may interfere with sexual performance. Ask about side effects, alternatives, and dosing options.
- ✓ Some treatments may cause vaginal dryness in women or erectile dysfunction in men. Talk with your oncology team about using vaginal lubricants and other options to make intercourse more comfortable or to help get or maintain an erection.

Fertility

A lot of things must go right for a couple to make a baby and a woman to carry a pregnancy to term and have a healthy baby. Cancer and its treatment can disrupt hormone levels, affect ovulation (women) or sperm production (men), cause erectile dysfunction (men), or make sex uncomfortable or painful.

- **Future children: If you think you may want to have children someday, talk with your doctor right away.** The type and dose of drug therapy used makes it hard to predict if a woman or man will become infertile afterwards. If your treatment can cause infertility and you want children, you will need to take steps, such as freezing eggs or sperm, before your treatment begins.
- **Do not get pregnant or father a child during drug therapy or for a few months afterwards:** Drug therapy can damage a woman's eggs and/or a man's sperm and cause birth defects. If there is damage to the egg or sperm, the embryo could be harmed, or the pregnancy may be lost. Talk to your doctor about how long you should take precautions once your treatment has ended.
- **Use condoms:** The drugs used in cancer treatment can stay in semen and vaginal fluids, so use a condom even if you are using other birth control methods.
- **Most cancer survivors can still choose to become a parent.** It might not happen the way you planned before cancer, but if you can be flexible, you'll find that you have options. These include infertility treatment, adoption, or using a donated egg or embryo (sometimes with a surrogate to carry the pregnancy).



Preventing Infection

Key Points

- When germs (bacteria, viruses, fungi) enter your body and multiply, they can cause infection, illness, or organ and tissue damage.
- The nadir (lowest levels of infection-fighting white blood cells) lasts about a week. This is when you are at the highest risk of infection and should be extra careful.
- **Handwashing is one of the best ways to prevent infection.**
- No matter how careful you are, you may still get an infection during treatment.

It's important to understand what an infection is before you learn about the things that might lower your risk. Infection begins when germs (bacteria, viruses, fungi) enter your body and multiply, causing illness or organ and tissue damage. Cancer, drugs used to treat cancer, and other medications like steroids may increase your risk of infection by weakening your immune system.

Some drug therapies cause *neutropenia*, a decrease in the number of healthy white blood cells (neutrophils) that help protect you from infection. Neutropenia can be one of the more dangerous side effects of drug therapy. Generally, your white blood cells are at their lowest level between 7 and 12 days after a treatment. This low point is called the nadir and it can last up to a week. During the nadir you are at higher risk for infection. (Your risk is greater if your neutrophil count is very low or if the neutropenia lasts a long time.) Be extra careful during this time. You may be asked to take your temperature every evening and report any fever to your doctor.

Prevention Tips

- ✓ **Clean hands prevent infections. Hand washing is one of the best methods for preventing the spread of infections.** When?
 - before eating, drinking, or taking medication
 - after using the bathroom, coughing, sneezing, or blowing your nose
 - before touching your eyes, nose, mouth, contact lenses
 - before and after performing any care with your IV lines, catheters, or bandages
 - after touching things in the environment that are often touched by others
- ✓ **Vigorously wash hands with soap and water for 20 seconds.**
 1. Use warm water. Hot water can dry your skin.
 2. Use liquid soap or dry bar soap.
 3. Rub your hands together for 20 seconds. Wash your thumbs, in between your fingers, the back of your hands, and under fingernails.
 4. Rinse well with warm water. If soap stays on your skin, it can make you itchy.
 5. Use paper towels to pat hands dry and turn off faucet. Use an elbow to push dryer button.



- ✓ Use alcohol-based hand sanitizers if soap and water are unavailable or hands are not visibly dirty.
- ✓ Ask your providers, family, and caregivers if they washed their hands before touching you.
- ✓ **Practice good personal hygiene.** Your skin is your body's first line of defense against infection.
 - Bathe or shower regularly and use a mild soap.
 - Use a clean towel every day. Do not share towels with other people.
 - Examine your skin closely for rashes, redness, cuts that are not healing, or areas of irritation.
 - If you have bandages and they get wet, replace them with dry bandages right away.
- ✓ Avoid people who are sick. If it's flu and cold season, avoid large, close crowds.
- ✓ Take your temperature if you feel warm, flushed, chilled, or not well. Fever may be the only sign that you have an infection, and an infection during chemotherapy can be life-threatening.

More Tips

- ✓ Do not handle animal feces. Have someone else clean the litter box or pick up after your dog. If you must do it, wear gloves. After taking off the gloves, wash your hands.
- ✓ Get plenty of rest. Fatigue can stress your immune system.
- ✓ Eat a well-balanced diet with nutritious foods.
- ✓ Do not eat spoiled or expired foods or raw meat or seafood.
- ✓ Keep fruits and vegetables refrigerated.
- ✓ Thoroughly wash fruits and vegetables. Ask for a copy of *Food Safety for Cancer Patients* from your nurse or the staff in the Resource Center (located in cafeteria on 1st floor of the main hospital), or go to: [fda.gov/downloads/Food/FoodborneIllnessContaminants/UCM312761.pdf](https://www.fda.gov/downloads/Food/FoodborneIllnessContaminants/UCM312761.pdf)
- ✓ Get vaccinated to prevent illness but always talk to your healthcare provider first. Encourage people in your household to get vaccinated too.
- ✓ Avoid injury, even small cuts or tears in the skin can get infected.
- ✓ Wear shoes to protect your feet.
- ✓ Talk to your doctor or nurse about your risk. Here are some questions that you can ask:
 - Will my treatment or other factors increase my risk of a low white blood cell count?
 - Will you do anything special to help keep me from getting infections? What can I do?
 - If I get a fever does that mean I have an infection?
 - How will I know if I have an infection and what should I do?
 - How will you decide how to treat my infection?

Remember, sometimes infection occurs no matter how careful you are.



Safety Precautions at Home

Key Points

- When you have cancer, you can have a higher risk of falling. Medications can make you dizzy.
- Keep a list of your medications, why you take them, and the dose – bring it with you to appointments.
- Take precautions for 2-3 days after your treatment to avoid exposure to bodily fluids, which may contain toxic chemicals from your drug therapy.

Stay Safe - Prevent Falls

You may feel weak or tired from your treatments. Your medications may cause you to feel dizzy, have difficulty seeing or hearing, or cause a sudden drop in your blood pressure. Any of these may cause you to be unsteady on your feet.

These tips will help keep you safe at home.

- ✓ If you feel dizzy, weak, lightheaded, or unsteady, ask a family member or caregiver for help.
- ✓ If you have been lying down for a while, be sure to sit up for a few minutes before trying to stand. It can help with dizziness.
- ✓ Wear glasses or hearing aids when needed. Wear proper shoes that have non-skid soles.
- ✓ Avoid floppy slippers, bare feet, or loose stockings. Use your walker, crutch, or brace.
- ✓ Throw rugs are unsafe and should be removed. Keep commonly used items within easy reach.
- ✓ Be aware of all of your tubes or lines.
- ✓ Remember, medications can change the feelings in your toes and feet.

Stay Safe - Prevent Medication Errors

Keep a list of ALL the medications you are taking. Write down:

- ✓ the name of the medication and why you take it
- ✓ the strength of the medication (ex. 10 mg) and the dose you use
- ✓ how often you take it and how you take it (by mouth? by injection?)
- ✓ include over-the-counter products, herbal and other types of supplements, vitamins, minerals, and alternative/enhancement products



Bring this list to all your healthcare appointments and share this information with your doctors, pharmacies, and other healthcare providers.

It's Important to stay safe during your treatment.

- The medicines used to treat cancer can be very strong. You must use them exactly as your doctor prescribes.
- Drugs that prevent or manage side effects may also have some unpleasant side effects.
- A certain drug or dose may be life-saving for someone. That same drug or dose may cause someone else to become very sick or even die.
- Certain foods or other drugs may weaken, strengthen, or block the intended actions of a medication.
- ✓ Ask if you have any questions or concerns about your medications. When you pick up a refill at the pharmacy, look at the name and the medication. If it looks different or the name sounds different, ask the **pharmacist**, not the counter person.
- ✓ Use only 1 pharmacy (or 1 pharmacy chain) to fill all your prescriptions, whenever possible.
- ✓ Report any side effects to your doctor.

Stay Safe - Home Precautions after Drug Therapy

If you are on IV drug therapy, please follow these precautions for the first 48 hours after your treatment. They will help you avoid contact with toxic chemicals that can be found in a patient's body fluids (urine, vomit, blood, stool, saliva, sweat, semen, and vaginal secretions) after an infusion.

Be sure that someone is with the patient during this time as they may need some help.

- **Using the bathroom**
 - Close the lid of the toilet and flush two times after each use.
 - Depending on the drugs given, you may be asked to use a different toilet from others in the home, if possible.
 - Men should sit to urinate to avoid splashing.
 - After using the toilet, wash your hands with soap and water.
- **Contaminated items**
 - To throw away contaminated items: Put items in a sealed plastic bag and then in the trash.
 - You must wear gloves when handling the patients' body fluids. Then throw away the gloves and wash your hands.
 - After using any container or device for body waste, thoroughly wash your hands and the container/device with soap and water. Dry it with paper towels and throw away the towels.
 - Remove soiled absorbable disposable undergarments immediately and throw them away.
 - Sheets or clothes soiled with body fluids: Machine-wash twice in hot water with regular laundry detergent. Wash separately from other laundry. Do not hand wash. If not washing right away, put them in a sealed plastic bag.
 - **Accidental contact?** Wash the exposed area several times with soapy water and tell your doctors on the next visit. A single exposure may not do much harm, but repeated exposures take extra precautions to avoid repeated exposure.



Fever

Key Points

- Ask your doctor if your treatment is likely to cause fever – and why. Fever can be a sign of infection, which may be very serious, particularly if your immune system is weakened.
- If your white blood count is extremely low, you may have an infection but not have a fever.
- Fever is not always a sign of infection. Some cancers and drugs, and hormone imbalances, can cause a fever.

Your team will tell you when to report your fever. When you call, you may be sent to the Assessment & Treatment Center (ATC), our urgent care center, which is open 24/7. Please note the ATC is not a walk-in clinic, you must be referred by your Roswell doctor or the doctor-on-call.

In general, call if your fever:

- is 100.4° F (38°C) or higher
- causes chills or shivering
- does not respond to approved medication(s)
- lasts more than 24 hours, or if it returns within 24 hours
- is accompanied by new symptoms or by symptoms that are getting worse
- prevents you from eating or drinking

How a Fever Works

- A *pyrogen* causes your body's "thermostat" to be reset to a higher temperature. Your body creates heat to reach that temperature.
- Blood vessels in your arms and legs constrict and redirect blood to the internal organs, which raises the temperature of the blood. (With less blood in your arms and legs, you may begin to feel cold and add more blankets or clothes. This reduces heat loss and helps create more body heat.)
- Liver activity increases and produces heat.
- You may begin to shiver, and your muscles will release heat.
- These processes continue until you reach the new "set point", When there is too much heat, the hypothalamus tells your body to reverse the processes. Your blood vessels dilate, you begin to sweat and the fever breaks.
- *Antipyretic* drugs, such as aspirin and acetaminophen, may reset (lower) the set point.

What Should I Do If I Think I Have a Fever?

- ✓ If you start feeling hot or cold, or one and then the other, take your temperature every 2-3 hours and write down the results.
- ✓ **If your temperature hits 100.4° F (38°C) — or whatever level your doctor specified — call your doctor.**
- ✓ Drink a lot of fluids – especially water. Ice pops are a good choice if you have nausea. Avoid alcohol and caffeine.
- ✓ **Do not take aspirin, ibuprofen/Advil®, or acetaminophen/Tylenol® unless your doctor has said it is OK.**
- ✓ Don't push yourself; take it easy and rest.
- ✓ Put a cold cloth or ice bag on your head if you feel hot or your head hurts.

Tips

- ✓ If you have a fever and you've already spoken with your medical team, continue with fluids, rest, and cold cloths.
- ✓ Now is an important time to make nutritious food choices. Even when we are in good health, our bodies burn calories from the food we eat to get energy to keep our bodies working. This requires a constant supply of water and fuel – protein, carbohydrates, and fats. **When we are stressed by fever, infection, cancer treatments, or wound healing, our need for fuel grows.**
- ✓ Give your body the fluid and food that supply the building blocks it needs. Be smart.
- ✓ **Choose water and foods that contain a lot of water, such as chicken soup.**
- ✓ Fresh fruits provide vitamins and antioxidants. (Wash them thoroughly.)
- ✓ Eggs, poultry, fish, milk, meat, quinoa, beans, lentils, nuts/nut butters, cheese are all high in protein.
- ✓ Greek yogurts with live and active cultures can provide probiotics and protein.
- ✓ If you are in treatment, take fevers seriously and deal with them right away.
- ✓ See *Preventing Infections* section for more ideas on how to lower your risk.



Fatigue

Key Points

- ✿ Fatigue is common during cancer treatment but can be managed.
- ✿ Minor adjustments can be made to your daily activities that may help you to save energy.
- ✿ **Exercise has been proven to fight fatigue and increase energy.**
- ✿ If your fatigue is persistent or symptoms worsen, call your doctor or nurse right away.

Fatigue, usually described as feeling tired, weak, or exhausted, affects most people during cancer treatment. Cancer fatigue can result from medication, as a side effect of treatment, from a lack of exercise/activity, or from the cancer itself. You may have mild fatigue, or you may feel completely exhausted. You may have short episodes of fatigue or it may last for several months after you complete treatment.

Feeling tired all the time can be difficult. Getting overtired can make everyday living very stressful, make you more likely to feel sick, and make it harder for you to cope with both. Listen to your body and rest if you need to.

Use Your Energy Wisely

We know it isn't easy but try to make a few changes, so you don't become exhausted.



- ✓ If you are working, see if you can reduce your working hours.
- ✓ Arrange help with childcare on treatment days and for a couple of days afterwards.
- ✓ If you are looking after children yourself, involve them in a quiet activity that you can supervise or participate in while sitting: Drawing pictures, board games, watching TV, or playing computer/video games.
- ✓ Sit to complete tasks whenever possible: prepare meals and wash dishes while sitting, use a chair in the shower.
- ✓ When standing, lean against a countertop or wall to take weight off your feet.
- ✓ Practice proper body movements. Don't bend, twist, or reach if you don't have to.
- ✓ Slide objects to move them instead of lifting and carrying them.
- ✓ Use electrical appliances to complete a job.
- ✓ Use a wheeled cart or bag to move objects from one place to another.
- ✓ Use both hands when possible.

- ✓ Use pieces of rubber shelf liner to prevent plates from sliding.
- ✓ Wedge mixing bowls into a drawer so you can stir with both hands.
- ✓ Use a hands-free device to talk on the phone.
- ✓ Use paper plates and plastic cups instead of ceramic or glass.
- ✓ Use prepared meals. Check with your local grocery store to see if they will deliver groceries. If you are age 60 or over, you can contact Meals on Wheels. If you are under age 60 and need assistance with meals, talk to one of our Social Workers.

Set Priorities and Make Plans

- ✓ Eliminate or reduce tasks that aren't that important to you.
- ✓ Delegate tasks to friends or family members who offer to help.
- ✓ Consider hiring a service or a local teen to clean or do yard work so you don't have to do it.
- ✓ Keep your commonly used items in easily accessible places.
- ✓ Gather everything you will need to complete a task before starting so it is in one place.
- ✓ Cook larger quantities and freeze or refrigerate extra portions for later.
- ✓ Take breaks when you need to.
- ✓ Schedule enough time to complete tasks. You use more energy when you are rushing.
- ✓ Try keeping an activity journal to see if there are times of the day when you have more (or less) energy, and what activity or tasks you find especially tiring.

Get Moving!

Plan an exercise to do every day despite the fatigue. Studies show that exercise helps fight fatigue and increases the amount energy we have. You should exercise even when you don't feel like it, even if it is only for a few minutes at a time.

Talk with your doctor before beginning any exercise program. When given the OK by your doctor, try some of these suggestions:

- Aerobic activities – walking, running, rowing, bicycling, or dancing – are an excellent way to exercise and get energy. If your fatigue is more severe and these activities are impossible, try getting dressed and walking around the house. **The important thing is to move about as much as you can, even if it is just a little.**
- Ask your doctor if you need to see a physical or occupational therapist to make an exercise program for you that will help increase your energy and endurance.



Taste Changes

Key Points

- ❁ Mouth sores and taste changes may make it hard to eat or drink enough to get proper nutrition.
- ❁ There are simple steps you can take to if you have a metallic taste in your mouth or to help with altered or odd tastes and flavors.
- ❁ Tell your doctor if you have stopped eating because of changes in taste, mouth sores, or other symptoms.

Taste changes, which affect about half of those in drug therapy, can make it very hard to get the calories and nutrients you need for healing and to stay well. If food and drink don't taste good to you – or worse, if they actually taste bad – you won't eat and drink as much as you need. If you don't eat and drink as much as you need, it can lead to weight loss, electrolyte imbalance, dehydration, and nutritional imbalance. Talk to your doctor if you are having trouble with taste.

What is the Cause?

The exact cause is not clear. Chemotherapy attacks cells that reproduce quickly, which may be part of the problem. Another possibility, some people make an association in their mind between chemo and an unpleasant symptom such as nausea or diarrhea, and it has affected their sense of taste or their desire to eat.

The chemo drugs most often associated with changes in taste are the platinum drugs (carboplatin, cisplatin), cyclophosphamide, 5 FU, doxorubicin, paclitaxel, vincristine, and dacarbazine. Vincristine, cisplatin, and cyclophosphamide are likely to cause a metallic taste in your mouth *during the infusion*. Immunotherapies such as IL-2 and interferon can also cause taste changes. Patients report that foods taste spicier, blander, or bitter.

Tips

- ✓ If something smells good to you right now – eat it right now.
- ✓ Stay away from foods that have odors that bother you.
- ✓ Don't eat for a few hours before and after your drug therapy.
- ✓ Go for stronger flavors – herbs, spices, sugar, lemon or citrus (Don't have citrus if you also have mouth sores).



- ✓ Eat chicken, eggs, fish, nut butters, or other proteins instead of beef, which often causes a metallic taste.
- ✓ Use prepared meals from stores, restaurants, family, or friends.
- ✓ Do not smoke – it can make it worse.
- ✓ Drink more liquids – at least 2 quarts a day to stay hydrated (but not right before eating).
- ✓ Keep your mouth clean and healthy. Brush your teeth before and after every meal.
- ✓ Use plastic forks and spoons if your food tastes like metal.
- ✓ Make mealtime pleasant.
- ✓ Avoid your favorite foods because if it doesn't taste the way you remember it, you will be disappointed and not eat.
- ✓ Add healthy fats to your diet.

Tips for Problems That Make it Hard to Eat

- ✓ **Mouth sores:** Choose easy-to-eat foods: bananas, watermelon, strawberries, pears, applesauce, rice, toast, peanut butter, popsicles, Jell-O®, Boost® or Ensure® (protein shake), cottage cheese, yogurt, creamed soups, cheese, dried fruits, milk
- ✓ **Metallic taste in your mouth:** Use plastic cutlery not metal silverware. Try cold foods. Try using a little sweetener, like maple syrup
- ✓ **Metallic or bitter taste:** Try mints, gum, or ice
- ✓ **Food tastes too sweet:** add drops of lemon or lime
- ✓ **Too salty:** add ½ teaspoon of lemon juice
- ✓ **Too bitter:** add a little sweetener
- ✓ **Food tastes bland:** marinate it before cooking, add spices before you eat. Add sea salt
- ✓ **Red meat tastes odd:** switch to other sources of protein chicken, eggs, fish, turkey, beans, etc.
- ✓ **Any bad taste in your mouth:** Suck on hard candy with strong flavor like mint or lemon. Try rinsing out your mouth with ginger ale

Talking with Your Doctor

- Review ALL your medications with your doctor or clinical pharmacist to see if any combination of medications is adding to your taste changes. If so, discuss if any changes are possible.
- Tell your doctor if you:
 - have stopped eating or drinking because of changes in taste
 - have lost 5 pounds or more
 - have mouth sores, heartburn, constipation, depression, nausea, fatigue, or pain



Loss of Appetite

Key Points

- Drug treatment may change the way food tastes or cause side effects such as mouth sores that make it hard to eat.
- There are foods you can remove or add to your diet that will help you to maintain good nutrition and avoid weight loss.
- Call your doctor to report any symptoms that may be contributing to your decreased appetite or any significant weight loss or gains.

Eat well, especially during treatment for cancer. Be aware that drug therapy may change the way food tastes or smells. Side effects such as mouth sores and trouble swallowing can make it hard to eat. Nausea or fatigue can also result in a lack of appetite. Talk with your health care team if you are not hungry or if you find it difficult to eat. Don't wait until you feel weak, have lost a lot of weight, or are dehydrated.

Tips to Help Your Appetite

- ✓ Being active can increase your appetite. Try a short walk every day.
- ✓ Eat a healthy snack every few hours rather than 3 large meals.
- ✓ Make the most of any food that interests you, like 'comfort foods' from your past.
- ✓ If a food's smell bothers you, don't eat it.
- ✓ Use a small plate and put just a little bit of food on it.
- ✓ Eat with family or friends or watch television while you eat.
- ✓ Eat snacks and meals on a schedule and keep to the schedule, even if you are not hungry.
- ✓ If you aren't eating a lot, make the most of each spoonful. Choose high protein, high calorie foods. Add protein powder to your food.
- ✓ Choose foods that are smooth or moist (baby food versions of pureed fruits).
- ✓ Drink 2 quarts a day to stay hydrated but don't have a big glass right before a meal or snack.
- ✓ Make it easier to eat. Keep small portions of foods around. Will someone shop or cook for you?
- ✓ Eat your food at room temperature. Stay away from foods that are very hot or very cold (temperature).
- ✓ Stay away from spicy, heavy, and acidic foods and foods high in salt or sugar.

Tips for Problems That Make it Hard to Eat

- ✓ **A bad taste in your mouth:** Suck on hard candy with strong flavor like mint or lemon. Try rinsing out your mouth with ginger ale. If it is a metallic taste, use plastic cutlery. Try cold foods.
- ✓ **Mouth sores:** Choose easy-to-eat foods: bananas, watermelon, strawberries, pears, applesauce, rice, toast, peanut butter, popsicles, Jell-O®, Boost® or Ensure® (protein shake), cottage cheese, yogurt, creamed soups, cheese, dried fruits, milk.
- ✓ **Nausea:** Bananas, watermelon, pears, applesauce, rice, toast, peanut butter, popsicles, Jell-O®, Boost or Ensure (protein shake), bland crackers, or dry cereal.
- ✓ **Constipation:** Walk and move around, eat high fiber foods, and drink 2 quarts a day (particularly water). Talk to your doctor about taking a stool softener or laxative.

Talking with Your Doctor

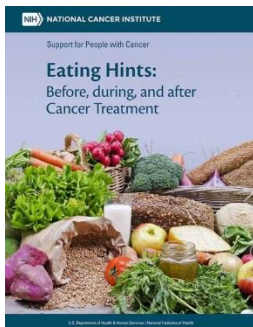
What your doctor needs to know: Tell your doctor about your symptoms that may be making your appetite/eating problems worse such as mouth sores, heartburn, constipation, depression, nausea, fatigue, or pain.

Medications

- Review ALL your medications with your doctor or clinical pharmacist to see if any combination of medications is contributing to your appetite problems. If so, discuss if any changes are possible – different medication, different dose, taking it at a different time of the day.
- If you have nausea, ask about medications. If you are already taking anti-nausea medications, are changes needed?
- Discuss the use of prescription medications to increase appetite.

Questions to ask

- What foods should I eat?
- Are there high-protein drinks or vitamins that can help me?
- How much water, or other liquids, should I drink each day?
- What exercises can help increase my appetite?
- Would it be helpful for me to see a registered dietitian (RD) since I am still losing weight?



Resource

For more ideas about how to get the nutrition you need, see the National Cancer Institute's booklet: *Eating Hints: Before, During, and After Cancer Treatment*. The book is available in the Resource Center for Patients & Families (located inside the hospital cafeteria on the first floor), in the Health Library in the patient portal, and online at:

www.cancer.gov/publications/patient-education/eating-hints



Nausea and Vomiting

Key Points

- Advances in drug therapies may prevent, lessen, or treat nausea or vomiting.
- Staying hydrated is very important. If OK with your doctor, drink water during your infusion. Drink 2-3 quarts of water a day – especially in the first few days after a treatment.
- Take note of the Prevention Tips to prepare yourself *before* the nausea begins.

- Nausea and vomiting are not always side effects of drug therapy and many people do not get either. For those who do, advances in drug therapies mean these side effects may be prevented, lessened, or treated.
- You may have nausea during treatment, within 24 hours (acute), or much later (delayed).
- Nausea may be caused by the medications' effects on the cells that line your stomach. It may also result from irritation to your mouth, esophagus, or stomach; or by affecting your sense of balance (like motion sickness).
- Ask your doctor/nurse if nausea or vomiting is a side effect of your drug regimen, when it usually occurs, how long it will last, and how they will prevent/treat it.
- Your doctor can prescribe anti-nausea (antiemetic) medications. You may need to be patient while they find the right drug or drug combination that will work best for you.
- It is important to treat nausea and vomiting to improve your quality of life and to avoid serious problems such as dehydration, malnutrition, electrolyte imbalance, and mental changes. Keep in contact with your doctors and nurses about how you are feeling.

Prevention Tips

- ✓ Eat 5 or more small meals or snacks during the day instead of 3 large meals.
- ✓ Drink most of your fluids between meals. At meals, only drink enough to keep food moist.
- ✓ Eat before you get too hungry.
- ✓ Eat dry crackers or cereal first thing in the morning. Nibble on them throughout the day.
- ✓ Rest often. If you've eaten in the last 2 hours, rest sitting up or with your head elevated.
- ✓ A light snack 1-2 hours before your treatment may help. Afterwards, wait 1 hour before you eat.
- ✓ Suck on hard candy, popsicles, or ice during your treatments.
- ✓ Take anti-nausea medication as directed.
- ✓ Rinse your mouth often to get rid of unpleasant tastes in your mouth.

Stay away from:

- ✗ fried, spicy, and fatty foods on treatment days and for 2-3 days afterwards
- ✗ foods with strong or unpleasant odors (including during cooking)
- ✗ caffeine and tobacco products
- ✗ clothes that press against your stomach and throat areas
- ✗ exercising right after eating... but a slow walk in fresh air may be helpful

Helpful foods	Foods to Avoid
Ice pops	Greasy, fried, oily, and fatty foods
Clear soups and sodas (drink flat soda or stir it well before drinking to get rid of the carbonation), and Gatorade®	High fiber foods: bran, oatmeal, fresh fruits, whole-grain breads, broccoli, corn, and beans
Weak tea, fruit juices, and nectars	Dairy products
White bread, rice, potatoes, pastas; creamed rice or wheat cereals; crackers; dry toast	Coffee, tea, energy drinks, and candy that contain caffeine
Bananas, applesauce, and cooked fruits	Acidic/ citrus fruits
Yogurt, pudding, cottage cheese, scrambled or soft boiled eggs, smooth peanut butter	Spicy foods
Cooked chicken/turkey (no skin), lean beef, and fish	Acidic foods and drinks
Liquid supplements, such as Ensure®	Alcohol

Have Nausea or Vomiting?

- ✓ Take anti-nausea medication as soon as you feel nauseous or as scheduled.
- ✓ Eat and drink foods at room temperature.
- ✓ Hard to eat or drink? Try a salty, bland food like pretzels to help retain fluids.
- ✓ Distract yourself with calm activities, such as reading.
- ✓ Losing weight or can't meet nutrition needs? Ask your doctor for a referral to our dietitians.
- ✓ Try integrative and relaxation techniques such as acupuncture, deep breathing, guided imagery, healing touch, listening to music, reading a book, or meditating.
- ✓ Try the 'BRAT' diet (**B**ananas, **R**ice, **A**pplesauce, and **T**oast). Note: The BRAT diet does not meet basic nutritional needs. If you cannot eat other foods in 2-3 days, call your doctor.
- ✓ If your nausea lasts 1-2 hours, skip eating and just sip water. If nausea lasts longer, you will need to find ways to get needed nutrients and fluids.
- ✓ If you vomit, wait an hour and try clear liquids. If you do not vomit, try small bites from the **Helpful Foods** list.
- ✓ Drink 2-3 quarts per day to avoid becoming dehydrated. Drink a variety of fluids to help provide the calories, sodium (salt), and other electrolytes your body needs. Broths are a good source of sodium, and some sports drinks have added electrolytes (check the labels).



Diarrhea and Dehydration

Key Points

- Stay well hydrated by drinking 2-3 quarts daily and limit products with caffeine.
- Eating bland, soft, low fiber foods may help in preventing diarrhea.
- Severe diarrhea may lead to dehydration which can be life threatening. Contact your doctor if you have a sudden attack of diarrhea lasting for more than 24 hours.

Diarrhea is very frequent and/or liquid bowel movements. It may be caused by your treatments, infection, or even by stress.

Long-term diarrhea may lead to dehydration (lack of water in the body), weight loss, and/or electrolyte imbalances such as low levels of salt and potassium. Your body needs water, salt, and potassium to work properly.

Prevention Tips

- ✓ Drink 2-3 quarts (4 cups = 1 quart) every day, unless your doctor restricts your fluid intake. Keep a water bottle with you to remind you to drink. Sip your liquids.
- ✓ Eat small amounts of soft, bland, low fiber foods frequently. Examples: banana, rice, noodles, white bread, skinned chicken, turkey, or mild white fish.

Avoid:

- ✗ very hot or very cold foods and drinks – they should be room temperature
- ✗ alcohol and tobacco products
- ✗ greasy, fatty, or fried foods
- ✗ raw vegetables or fruits
- ✗ strong spices
- ✗ whole grains breads and cereals, nuts, and popcorn
- ✗ gas forming foods and beverages (beans, cabbage, carbonated beverages)
- ✗ herbal supplements such as cayenne and ginseng

Limit or avoid products that with caffeine:

- Regular and diet colas, Dr. Pepper®, Sunkist Orange®, Mountain Dew®, A&W® cream soda
- Energy drinks such as Red Bull®
- Coffee, tea, chocolate
- Over-the-counter medications such as NoDoz®, Vivarin®, Excedrin®, Bayer Select®, Midol®, Anacin®
- Prescription medications such as Cafergot®, Fiorinal®, and Norgesic®

Have Diarrhea?

- ✓ Drink 8-10 glasses per day of clear fluids (water, broth, Jello®, Gatorade®, etc.) Liquids that you can see through at room temperature (about 72°-78°) are considered clear liquids.
- ✓ Supplements such as Ensure and Boost, as well as sweet clear liquids such as fruit juices may worsen diarrhea. It is helpful to sip on these liquids. Drinking small frequent amounts can get you the nutrition you need and help you tolerate them better.
- ✓ Eat/drink small amounts of food and liquid frequently during the day instead of 3 large meals.
- ✓ Take over-the-counter medication such as loperamide/Imodium®, Kaopectate® or Maalox® caplets, or Pepto® diarrhea control. Check with your doctor first.
- ✓ If your anal area becomes sore: clean gently with warm water and dry completely. Apply a water barrier cream like Desitin® to the area. Keep the sore area open to the air as much as you can.
- ✓ **Foods that may help: yogurt*, cottage cheese*, rice, noodles, potatoes, cream of wheat, farina, eggs (well-cooked but not fried), smooth peanut butter, white bread, well-cooked vegetables, chicken or turkey without skin, lean beef, broiled or baked fish, and canned peeled fruits.**
***Some people need to avoid milk and dairy products because lactose makes them sick.**
- ✓ **Avoid skins, seeds, and stringy fibers of unpeeled fruits; high fiber vegetables like broccoli, corn, dried beans, cabbage, peas, and cauliflower, even if cooked; foods high in sugar and/or high in fat; and the foods listed in the Prevention Tips section.**
- ✓ The BRAT (bananas, rice, applesauce, toast) diet can be useful for a day or two. Neither the BRAT diet nor a clear liquid diet meets your body's basic needs for calories or protein. Both diets should not be used for more than 1-2 days without your doctor's knowledge. Staying on the BRAT diet for too long may cause a zinc deficiency. Zinc plays a key role in your immune system, growth, and skin development. Adding chicken, meat, fish, or dairy products back into your diet as soon as possible can meet your body's need for zinc.
- ✓ If you get a sudden, bad attack of diarrhea, do not have anything except clear liquids* for 12-24 hours. This will give your intestines time to rest and replace the fluids you lost. Let your doctor or nurse know as soon as possible.
- ✓ Make sure your doctor approves any treatments, diets, or other measures that you are using.

Dehydration

- Dehydration is what happens when your body loses too much water.
- Early signs of dehydration may be hard to notice. Severe dehydration leads to changes in the body's chemistry, (electrolyte imbalances), which may become life-threatening. People with severe diarrhea should not be left alone to care for themselves.

Preventing Dehydration

- ✓ Take medications as prescribed by your doctor. If you are running low, ask for a refill.
- ✓ Take at least a teaspoonful of any clear liquid every minute.



Constipation

Key Points

- Causes: Some chemo and opioid medications, low fiber diet, lack of exercise, hormone or electrolyte imbalance, not drinking enough water, and overusing laxatives.
- Eating fiber rich foods, staying hydrated, and increasing physical activity will help get your intestines moving.
- There are many types of laxatives. Talk to your doctor about what's best for you.

Constipation is hard, dry stool that is hard to pass and/or going to the bathroom less often than normal (for you). Constipation occurs when the colon (bowel) takes too much water out of the stool. This happens when stool moves through the colon too slowly or when the colon absorbs water faster than normal. About half of all people with cancer have constipation. Common causes include:

- Cancer or cancer treatment that creates blocks the intestine, puts pressure on the nerves controlling the colon; or damages the cells lining the digestive tract.
- Medications for nausea or seizures, pain (opioids), vinca alkaloid chemo drugs such as vincristine/Oncovin®, vinblastine/ Velbe®, and vinorelbine/Navelbine®.
- Not enough physical activity, fiber in the diet, water (dehydration), or food.
- Heavy or long-term use of laxatives.
- Hormonal imbalances that change your metabolism such as low thyroid hormone levels.
- Electrolyte imbalances such as high levels of iron, calcium, or potassium.
- Depression.

Symptoms

- Feeling full/bloated, cramps, belly pain, gas, loss of appetite, no bowel movements for 2+ days, straining to go, feeling pressure in your rectum, nausea, or anal leaking* that looks like diarrhea.
* Stool that moves around a large amount of stool stuck in colon/rectum (impaction).




Prevention – The Better Option

- ✓ **Eat more fiber.** Fiber draws water into the stool and softens it. Add fiber to your diet *slowly* to avoid gas and bloating – 5 grams a day if OK with your doctor.
- ✓ **Eat and cook with foods that are natural laxatives** such as seeds, raisins, prunes, prune juice, bran, papaya, and fibrous vegetables (sweet potatoes, pumpkin, spinach, kale).
- ✓ **Drink 2-3 quarts (liters) per day, particularly water** to stay hydrated and keep the fiber moving through your colon. Hot drinks (cocoa, tea, hot water with lemon) can help stimulate the colon. Try to have a hot beverage and a high fiber food at breakfast.

- ✓ **Increase physical activity.** Even a short walk can help get your intestines moving. Always check with your doctor before starting any new activity.
- ✓ **Have a prevention plan.** If taking opioid medication, ask about a bowel routine to prevent constipation. Opioids slow down the colon and cause constipation.



Foods to Help with Constipation

Breads and grains	Fruits and vegetables	Snacks
<ul style="list-style-type: none"> • Bran or whole-grain cereals • Brown or wild rice • Cooked, dried peas and beans (such as pinto, black, or kidney beans) • Whole wheat bread or pasta 	<ul style="list-style-type: none"> • Dried fruit, such as apricots, dates, prunes, and raisins • Fresh fruit, such as apples, blueberries, and grapes • Raw or cooked vegetables such as broccoli, corn, peas, green beans, and spinach 	<ul style="list-style-type: none"> • Granola • Nuts • Popcorn • Seeds, such as sunflower 

Over-the-Counter Laxatives

- **Check with your healthcare team before using any of these products.**
- Do not use laxatives for more than 1 week without your doctor's approval.
- Laxatives can interfere with other medicines. Take other medicines 2 hours before or after a laxative. If you are not sure if your medicines might interact, ask your pharmacist.

Laxative Type	How it Works	Products
Stool softeners	Increases water & fat in the colon	<ul style="list-style-type: none"> • docusate/Colace®
Stimulants	Increases the colon's contractions and moves stool through colon faster	<ul style="list-style-type: none"> • bisacodyl/Correctol®, Dulcolax® • sennosides/Senokot®, Ex-Lax®
Bulk forming (fiber supplements)	Moves through the colon quickly, taking stool with it. Only works if you drink a lot of water!	<ul style="list-style-type: none"> • psyllium/Metamucil® • methylcellulose/Citrucel® • polycarbophil/FiberCon®
Osmotic preparations	Pulls water into the colon. Your doctor may combine an osmotic laxative with a stimulant laxative.	<ul style="list-style-type: none"> • magnesium hydroxide/Milk of Magnesia® • polyethylene glycol/Miralax® • sorbitol, magnesium citrate, lactulose, and glycerin suppositories
Lubricants	Keeps water in the colon (softens) & makes stools oily (easier to pass)	<ul style="list-style-type: none"> • Fleet® Mineral Oil Enema, mineral oil



Skin and Nail Changes

Key Points

- Your skin and nails may go through changes during your cancer treatment.
- You may be able to lessen skin problems by changing your skin care routine and being careful about the types of products you use.
- Use clean instruments to keep your nails clean and trimmed. Always check with your doctor before getting a manicure or pedicure.

Cancer treatments may cause a variety of skin and nail changes like rashes, dry skin, itching (pruritus), peeling skin, redness, sensitivity to the sunlight (burns), blistering, and brittle or discolored nails. Treatments can lower your immune system and increase your risk of infection. Some of these conditions can be serious. Talk with your health care team about whether your treatment is likely to cause problems. If so, ask what symptoms you should watch for.

Prevention Tips – Keep Skin Healthy

Simple things you can do to help prevent or minimize skin problems.

- ✓ **Stay Hydrated.** Drink plenty of water (if you're not on fluid restriction).
- ✓ **Moisturize!** Shower in lukewarm, not hot, water. After showering, put moisturizing lotion on your skin while it's damp. Look for a moisturizer that won't clog your pores. Only shower/bathe once a day. Apply moisturizer at least twice a day. If your skin is very dry, try body butter, which is thicker and provides more of a barrier. An effective moisturizer should be absorbed quickly and not leave a greasy residue. If strong smells bother you, look for fragrance-free products. Look for a tester bottle to make sure the claims on the label are true. There are products for sensitive skin (Lubriderm® Daily Moisture Lotion for Sensitive Skin, Cetaphil® Moisturizing Cream) but you may be better with a single ingredient product such as shea or cocoa butter.
- ✓ **Adjust your skin care to the season.** Skin tends to be drier in the winter (bitter cold & dryness from some heat sources) and oilier in the summer (heat & humidity) – neither extreme is good for your skin. Winter: avoid alkaline deodorant soaps (Dial®, Camay®, Ivory®) and use super-fatted soaps (Dove® Cetaphil®, Oil of Olay®, Aveeno®) with lukewarm water.
- ✓ **Stay out of the sun – or block it.** Wear long sleeves and long pants. Protect face, ears, and neck with a wide-brimmed hat. Wear a broad-spectrum sunscreen (SPF 30 or higher), especially on your hands, face, and neck. Ask your doctor if you should wear sun block every day.

- ✓ Treat your skin gently. Use products for sensitive skin (fragrance and alcohol free). Do not scratch, rub, or scrub your skin. Wear soft, non-irritating fabrics. Ask your doctor or nurse before you use hot or cold packs on your skin.
- ✓ Be as active as possible – short walks are good. If you cannot walk, move your arms and legs. This helps your circulation, which get nutrients to your skin and helps prevent skin problems such as sores.
- ✓ Make-up. Oil-free make-up tends to be well tolerated by all skin types. Look for make-up, lip balms, etc. that have sunscreen in them.
- ✓ Shaving. Women, if you get a rash after shaving your legs, do not shave again until your skin has healed completely. Men: If you get a rash on your face after shaving, skip shaving for a few days. Do not use perfumed products on your face such as after-shave.
- ✓ Tell your nurse right away if your skin starts to burn or hurt during your drug therapy.

Have a Rash?

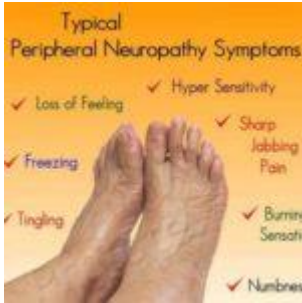
- ✓ Ask your doctor or nurse how to clean the area. (In general, keep the area clean and dry.)
- ✓ If your doctor prescribes a cream for your rash, use it exactly as your doctor directs.
- ✓ Talk to your doctor before using any over-the-counter product on your rash or taking antihistamines.

Prevention Tips – Keep Nails Healthy

Problems with your nails can develop weeks or months into your treatment and may continue after you finish treatment. Your fingernails and toenails can become dry and develop lines and ridges. The nail beds can turn brown or black, and nails may even fall off. To care for your nails, we recommend:

- ✓ Do not bite your nails.
- ✓ Avoid fake nails or wraps.
- ✓ Check with doctor before getting a manicure or pedicure. If the risk of infection is too high and you want to paint your own nails, use a formaldehyde-free polish such as Pacifica 7 Free Nail Color or Bliss Genius Nail Polish) and non-acetone polish remover (check label), which are gentler.
- ✓ Trim nails often. Cut nails short and keep them clean, using clean nail instruments. Smooth any jagged edges and remove hangnails right away so you don't catch them on something and tear them off.
- ✓ Protect your hands. Wear gloves when you wash the dishes, work in the garden, or clean the house, especially when using harsh chemicals
- ✓ Tell your care team if one of your nails is loose or falls off.





Pins & Needles & Numbness - Peripheral Neuropathy (PN)

Key Points

- PN is damage to the nerves outside of the brain and spinal cord – usually in hands and feet.
- Symptoms: Numbness, tingling, burning, and increased or decreased sensitivity, which raises your risk of injuries like burns and cuts.
- To date, there is no way to prevent PN and there is no cure, though it may go away on its own.
- If you get PN, there are things you can try to relieve symptoms like stiffness, and to lower your risk of injury.

Overview

- Peripheral neuropathy, or PN, occurs when peripheral nerves are damaged. Peripheral nerves are nerves located outside of the brain and spinal cord.
- There are two types of peripheral nerves.
 - **Sensory nerves** help you feel pain, touch, temperature, position, and vibration.
 - **Motor nerves** help you move and maintain muscle tone.
- The small sensory nerves in the fingers, toes, hands, feet, arms, and legs are the most commonly affected.
- If your drug therapy can damage nerve tissue, you will be asked if you have any PN symptoms **before** you begin drug therapy to establish a baseline. PN might begin sooner or be more severe in people who already have PN symptoms.
- The strength and dose of your drug therapy play a role in PN. Symptoms may appear after the drug(s) have built up in your system over several treatments.
- PN symptoms usually appear in a “stocking-glove” pattern, meaning they stop at wrists or ankles.
- Symptoms can include numbness, tingling (pins & needles), burning or pinching feeling, increased or decreased sensitivity to hot or cold temperatures, and/or increased or decreased sensations of pressure or pain. Symptoms may:
 - increase your risk of injury (getting a burn because you couldn’t feel that the pot or water was hot or having a cut get infected because you did not know it was there)
 - make it more difficult to button or zip your clothes
 - cause pain when a certain fabric brushes against your skin

- Though less common, motor nerves can be affected by PN. Symptoms include dizziness when you stand or sit up quickly, problems with balance or walking, problems with urination or bowel movements, and changes in your blood pressure or the regularity of your heart beat (pulse).
- In many cases, PN will gradually improve over time once treatment is over. For some drugs like cisplatin and oxaliplatin, it may get worse before it gets better.
- To date, there are no known ways to prevent PN. Results of studies so far have been mixed or inconclusive, so research continues.

Have Peripheral Neuropathy?

- ✓ Stay as active as you can to help keep your muscles working. If you exercise in a gym, tell the instructor that you have peripheral neuropathy and ask for instructions.
- ✓ Foot and hand massages may help relieve stiffness. After the massage, remember to clean the lotions and creams off your hands and feet.
- ✓ Have someone else check the water temperature before you take a shower, wash dishes, etc. If no one is available, test the water using a thermometer or use a part of your body that is not affected by PN.
- ✓ Get rid of throw rugs and any other obstacles that can increase your risk of falling or tripping.
- ✓ Oven mitts, gloves, socks, and shoes – protect your hands and feet, particularly when handling hot items or when you are out in severe weather.
- ✓ Ask about balance training and/or physical or occupational therapy.
- ✓ Use extra care when you are in the shower, on stairs, or handling sharp objects.
- ✓ Ask if using a walker or other assistance device would be helpful.
- ✓ Roswell's Supportive Care Center can assist with the most up-to-date ways to manage PN symptoms.
- ✓ Ask your nurse for the patient education brochure, *Peripheral Neuropathy* for more information. This brochure is also available:
 - in the Resource Center (Open 9 a.m. – 4 p.m., Monday – Friday. Located on the 1st floor of hospital, inside the cafeteria.)
 - in the Health Library in the Patient Portal



Bladder Health and Urinary Problems

Key Points

- Drink plenty of water or fluids before and after the days you have drug therapy unless your doctor has told you to cut down on your fluids.
- There are steps you can take to help avoid a urinary tract infection (UTI).
- Frequency, urgency and cloudy urine, or signs of a urinary tract infection or UTI. If you think you may have a UTI, call your doctor immediately.

After your infusion, your body breaks down the drugs and often gets rid of them by excreting them in the urine. The waste from these broken-down drugs can be irritating or damaging to the bladder as the urine passes through it. They can cause inflammation and bleeding. Though rare, it is possible for severe and/or long lasting irritation to lead to permanent damage. Bladder damage is more likely in folks who have had radiation to the bladder or pelvic area, have a history of persistent bladder or urinary tract infections, or have a low platelet count.

Drug therapies that commonly cause bladder irritation include:

- cyclophosphamide (Cytoxan®)
- ifosfamide (Ifex®)
- drugs that are put directly into the bladder such as mitomycin and BCG (Bacillus Calmette-Guerin)

Ask your doctor or clinical pharmacists about the drugs in your treatment plan. Could they cause changes in your urine or your urinary habits? If so, what symptoms do you need to report to your doctor?

Ways to Prevent or Manage Urinary Problems

Your healthcare team will take steps to prevent bladder irritation and damage such as:

- giving you extra fluids through an IV (intravenous)
- giving you a drug called Mesna® (uromitexan) that protects the bladder
- controlling any bladder bleeding that occurs

What You Can Do

- ✓ **Drink!** On treatment days, drink extra fluids before you go and for at least 24 hours afterwards. You want to keep your urine pale yellow to clear. Drink 2-3 quarts/liters of fluid a day – preferably water – unless your doctor restricts your fluids. Stay away from things that can make bladder problems worse such as caffeine, alcohol, spicy foods, and tobacco products.
- ✓ **Prevent urinary infections.** Ask your nurse or doctor about ways you can lower your risk of a urinary tract infection (UTI). Women and the elderly are at higher risk. For someone on cancer drug therapy, a UTI should be treated immediately because it can turn into a very serious problem. Here are some tips to help avoid getting a UTI.
 - Don't hold in your urine - go to the bathroom often.
 - Wear loose pants and cotton underwear. Avoid pantyhose.
 - Take showers instead of baths.
 - When you go to the bathroom, wipe from front to back. Clean with soap and water, if possible.
 - Check with your nurse before using any products near your genitals (talc, creams, and lotions).
 - If you use a catheter, learn how to use it safely so you don't get an infection.



Symptoms of a Bladder or Urinary Problem

- Pain or burning when you urinate
- Cloudy or red/rusty colored urine
- Need to urinate often (frequency)
- Intense need to urinate (urgency)
- Trouble emptying your bladder completely
- Pain above your bladder and/or in your pelvic area
- Bladder spasms or cramps

Questions for your Doctor

- What symptoms or problems should I call you about?
- What steps can I take to feel better?
- How much should I drink each day? What should I drink?
- What foods and drinks should I avoid?



Chemo Brain – Memory and Concentration

Key Points

- Forgetfulness, poor concentration, lessened ability to multitask and difficulty processing information are some common symptoms of chemo brain.
- There are things you can do to strengthen your memory, stay organized and improve concentration.
- If living with chemobrain makes you anxious or sad, there are resources available to help you manage any emotional concerns or develop ways to cope.

Chemo brain refers to changes in your abilities to remember and think clearly as a result of cancer treatment. Originally, it was thought to be a result of chemotherapy, but studies show that patients having other types of treatment can have the same issues. Science is still looking for the cause(s). The effects can be a worsening of a pre-existing issue, or a new change in function. Some people get worse during treatment and then gradually improve when treatment ends. For others, the problems last a long time or become permanent.

Symptoms

- Forgetfulness, memory lapses, trouble recalling some words
- Problems concentrating or focusing
- Lessening or loss of the ability to do more than one thing at a time or to complete a task with multiple steps, difficulty with organization
- Taking longer to process information or instructions

Managing Symptoms

If you are finding it difficult to think clearly or having lapses of memory, try some of these tips.

- ✓ Start a journal to track the time and place you first experienced chemobrain, what you were doing at the time, what medications you are taking, how frequently you have symptoms, and anything you've noticed that makes your symptoms better or worse.
- ✓ Talk to your doctor (bring your journal). Ask if they know why you are having these issues, if they could be related to something that is treated more easily (electrolyte imbalance, low blood counts), and what you can do to improve things.
- ✓ Know your limitations. Complete one task (or step) at a time. Keep a positive attitude. Learn to ask for help. Some people use humor to help them through frustrating moments caused by forgetfulness or distraction.



Help with Memory

- ✓ Keep your mind active. Do word or number puzzles (Sudoku). It is likely that any brain stimulation may be helpful so play games, take a course, or join a book club.
- ✓ Be active. Regular physical activity and eating healthy foods is good for your body and can make you feel more alert.
- ✓ Sleep. Make sure you get plenty of rest. Fatigue can cause you to be less alert and focused.
- ✓ Tell your family member or friend what you are going through, so that they'll understand if you forget things. They may be able to help and encourage you.
- ✓ When you put something on the stove or in the oven, set a timer. If you have a smart phone, you can use the timer on the phone.
- ✓ Repeat information out loud after someone gives it to you and write down important points.

Get Organized

- ✓ Use a planner (paper pad, phone, or tablet) to create a place where you can write down what you need to do. Cross out tasks as you complete them. Use it to stay on top of your appointments, tasks, and special occasions.
- ✓ Organize your environment. Keep things in familiar places so you'll remember where they are. Put a basket by the front door for items you use every day like keys, cell phone, etc.
- ✓ Use sticky notes as reminders.
- ✓ A Navigation app or GPS are very handy and not just for long distance travel.



Improve Focus and Concentration

- ✓ Avoid distractions. Work, read, and do your thinking in an uncluttered, peaceful environment to help you focus.
- ✓ Have conversations in quiet places. This minimizes distractions and lets you concentrate better on what the other person is saying.
- ✓ Train yourself to focus. Take extra time to think about or picture what you're doing. Repeat things out loud to yourself. Hearing cues gives your memory an extra boost.

Who Can Help with Chemobrain?

- If living with symptoms of chemobrain makes you anxious or sad, contact Roswell Park's Department of Social Work at **716-845-8022**, or ask for a referral to meet with a Roswell Park psychologist for further evaluation.
- *CancerCare* offers social workers to help you manage any emotional or practical concerns that may be causing chemobrain and help you develop ways to cope. To speak with a professional oncology social worker, free of charge, call **800-813-HOPE (4673)**.
- *Neuropsychology* is concerned with how the brain and nervous system influence a person's mental processes and behaviors. Neuropsychologists focus on how illness or injury affects the brain and an individual's cognitive functions and behavior.



About Medical Marijuana (Medical Cannabis)

Key Points

- THC and CBD are two compounds in marijuana that may be helpful for pain, nausea, poor appetite, and muscle spasms.
- In NYS, you must be certified by a registered medical provider and then register in the NYS medical marijuana program.
- Once approved you can get your products at a dispensary. Medical marijuana is not covered by health insurance.

The term medical marijuana, or medical cannabis, refers to using the cannabis plant or its extracts to treat symptoms of illness. Tetrahydrocannabinol (THC) and cannabidiol (CBD), two of the main compounds in the cannabis plant, can be useful in treating pain, nausea, and poor appetite.

Medical marijuana does not cure cancer. It has been shown, however, to help with some symptoms common to cancer patients such as chronic pain, nausea, vomiting, poor appetite, and some forms of muscle spasms. There is ongoing research for new applications for medical marijuana to help treat new symptoms or diseases while ensuring patient safety. **Please be aware that using medical cannabis may disqualify you from participating in some clinical trials.**

Forms of Medical Marijuana Available in New York State

There are several products available. (NY does not allow smokable or edible forms)

- Vape cartridge/pen – takes effect quicker, doesn't last as long
- Capsules or tablets – takes some time to work but effects last longer
- Oil
- Oral spray
- Powder

Side Effects

In addition to the benefits, such as treating nausea and pain, there are several risks. Possible side effects include increased heart rate, confusion, difficulty thinking, and mood changes. Long term risks are higher for children whose brains are still developing but memory problems may develop in adults too. Marijuana is a controlled substance and your use of this drug will be monitored.

Cost and Insurance

As of April 2018, the NYS Dept. of Health has waived the \$50 activation fee for all patients and their designated caregivers. While NY law does not require or prohibit insurers from covering medical marijuana, it is still a Schedule 1 controlled substance at the federal level, so it is not covered by insurance. You may want to start with a 5-day supply (instead of a 30-day supply) to see how well it works for you. You cannot return unused product. Prices vary between dispensing facilities.

The Process

In January, 2022, New York dropped the requirement of a qualifying condition for the medical marijuana program. This means that doctors and other medical practitioners can prescribe it for any condition if they feel it cannabis would be helpful. A medical provider, such as that that work at Roswell Park's Supportive and Palliative Care Program can evaluate you and get you enrolled in the program.



- ✓ We will ask for your photo ID, such as a NY State driver's license, and make a copy for our records. We will enter your personal information on the NYS Department of Health website to certify you and then give you the paper certification document.
- ✓ You Apply for Registry ID Card. Online: For instructions, go to <https://cannabis.ny.gov/patients> and go to *How to Register*. You will need the certification form given to you, proof of identity, a photo, and proof of NY residency. If you have changed your name, you will also need proof of name change. You can see what documents are acceptable for identity and residence at: https://cannabis.ny.gov/system/files/documents/2022/01/Acceptable_Proof_Requirements.pdf
- ✓ You can also select 1 or 2 caregivers who can register and buy for you. Each caregiver must get their own registration.
- ✓ Take your ID card and medical certification letter to an NY State-approved dispensary. Addresses and hours can be found at www.health.ny.gov/mmp by clicking on Where to Purchase Products.

More Information



- **NYS Office of Cannabis Management**
<https://cannabis.ny.gov> The Marijuana Regulation and Taxation Act (March 2021) legalized adult use of cannabis and created a first in the nation comprehensive regulatory structure to oversee the licensure, cultivation, production, distribution, sale and taxation of medical, adult-use and cannabinoid hemp within New York State.
- **NYS Medical Marijuana Program**
<https://cannabis.ny.gov/medical-cannabis> Program information, registration for patients and designated caregivers, and locations of dispensaries
- National Institute on Drug Abuse: Marijuana as Medicine (Revised July 2020)
<https://nida.nih.gov/publications/research-reports/marijuana/letter-director>



Support and Resources

Cancer is a complex disease that can affect many aspects of life. We have created a list of trusted resources - at Roswell, in the community, and beyond. For more information, talk to your clinicians, stop by or call the Roswell Park Resource Center for Patients & Families at **716-845-8659**, or call **1-800-ROSWELL (1-800-767-9355)**.

At Roswell Park

- **Resource Center for Patients & Families: 716-845-8659.** Mon-Fri, 9 a.m. – 4 p.m.
www.roswellpark.org/patients/treatment-services/supportive-services/resource-center Friendly staff, cancer and support information, DVD lending, blankets, laptop loans (inpatients), and complimentary wig/hat programs. Hospital, 1st floor.
- **Acupuncture:** Offered in the Survivorship and Supportive Care Center at the main hospital and at our Amherst satellite. Phone: **716-845-3680**.
<https://www.roswellpark.org/cancertalk/202202/using-acupuncture-relieve-side-effects>
- **Cancer Coach: 716-845- 4432** For more information or to request a Coach for support during treatment or to become a Coach yourself, call or, on the web, go to:
<https://www.roswellpark.org/cancer-care/support/cancer-coach>
- **Elevate Salon:** Pretreatment haircuts and wig styling are among the services offered. Located on 1st floor of Clinical Sciences Center (near Breast Center) Hours: Mon – Fri 9am – 4 pm. **716-845-8659**.
<https://www.roswellpark.org/cancer-care/support/elevate-salon>
- **Financial Assistance & Concerns: 716-845-4782**
- **Genetic Counseling: 716-845-8400.** Questions about genetic testing for you or your family.
- **Hospitality Room:** Hours: Mon – Fri, 8 a.m. – 4 p.m. Hospital, ground floor near Radiation Medicine.
- **Legal Care at Roswell Park: 716-845-6475.** Email: LegalCare@RoswellPark.org Free, confidential consultation for patients with health-related work, insurance, or financial problems.
<https://www.roswellpark.org/cancer-care/support/legal-care-0>
- **Nutrition Department: 716-845-2398.** Nutrition issues related to cancer diagnosis or treatment. Ask your nurse for a referral or call to speak with a clinical registered dietitian nutritionist (RDN).
- **Online Community:** Safe, private, and supportive place for anyone whose life is touched by cancer. Available 24/7. Moderated by a Roswell patient educator. <https://community.roswellpark.org>
- **Outpatient Pharmacy: 716-845-8999.** Open Mon-Fri, 9 a.m.-6 p.m. and Sat 9 a.m.-1 p.m. Prescription services, free delivery within 150 miles. Hospital, 1st floor, next to the cafeteria.

At Roswell Park (cont.)

- **Patient Portal – MYROSWELL: 1-800-ROSWELL (1-800-797-9355).** <https://my.roswellpark.org>
Secure access to your appointments, test results, and messaging with your medical team.
- **Rehabilitation Services: 716-845-3271.** Physical, occupational, and lymphedema therapy.
- **Social Work: 716-845-8022.** Social, emotional, lodging, translation, and transportation issues, 24/7; free and confidential. <https://www.roswellpark.org/cancer-care/support/social-work>
- **Supportive & Palliative Care Center: 716-845-8214** (or ask your doctor for a referral). Symptom management, counseling, and spiritual support at any time after diagnosis.
 - **Pain Management: 716-845-4595**
 - **Spiritual Care Services: 716-845-8051**
 - **Psychology Department: 716-845-3700**
- **Survivorship & Screening Center: 716-845-4800, option 1.** Offers a wide range of services, workshops and cancer support programs to help you manage any emotional, physical and spiritual challenges as you move beyond treatment. <https://www.roswellpark.org/survivorship>
- **The Young Adult Cancer (AYA) Program:** Offers nationally-ranked comprehensive cancer care, support, and services for those in their 20s and 30s, and their families, such as fertility issues. [roswellpark.org/patients/treatment-service/supportive-services/aya](https://www.roswellpark.org/patients/treatment-service/supportive-services/aya)
- **Tobacco Treatment Services: 716-845-7851.** Email: treattobacco@roswellpark.org Website: <https://www.roswellpark.org/cancer-care/support/tobacco-treatment-services>
NYS Smokers Quitline: 1-866-NY-QUITS (1-866-697-8487) nysmokefree.com
- **Wellness Programs:** Creative arts, yoga, Reiki, and meditation programs and events. <https://www.roswellpark.org/cancer-care/support/wellness>

Local

- **Livestrong @ the YMCA: 716-839-2543** (Amherst). **716-674-9622** (Southtowns). Physical activity program for cancer patients.
- **Center for Hospice & Palliative Care: 716-686-8077.** Website: www.hospicebuffalo.com
Provides comfort (palliative) care any time after diagnosis and hospice care at end of life. Grief support.

National Organizations and Online Resources

- **National Cancer Institute** (NCI): **1-800-4-CANCER** (1-800-422-6237) [cancer.gov](https://www.cancer.gov) Live chat available. Part of the National Institutes of Health. Information on cancers, treatments, support, research, clinical trials, and complementary & alternative therapies
- **Cancer Support Community**: **1-888-793-9355** cancersupportcommunity.org Live chat available. CSC's mission is to ensure that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community. CSC's alphabetical listing of organizations' names, contact information, and services/programs offered: cancersupportcommunity.org/resources
- **CancerCare**: **1-800-813-HOPE (4673)** [cancer.org](https://www.cancer.org) Free professional support services and information to help manage the emotional, practical, and financial challenges of cancer. Counseling, support groups, financial assistance, community programs, educational workshops, and publications
- **Cancer.net**: [cancer.net](https://www.cancer.net) Patient centered site with information from the American Society of Clinical Oncology (ASCO) on cancers, coping with cancer, research, and survivorship.
- **Leukemia & Lymphoma Society**: **1-800-955-4572** [lls.org](https://www.lls.org) Live chat available. Provides support and information on blood and lymph cancers and quality of life
- **National Comprehensive Cancer Network's (NCCN) Patient & Caregiver Resources**: [nccn.com](https://www.nccn.com) Not-for-profit alliance of 27 leading cancer centers that brings together oncology experts to create treatment guidelines for cancers. This site offers patient versions of the NCCN treatment guidelines.
- **American Cancer Society**: **1-800-227-2345** [cancer.org](https://www.cancer.org) Live chat available. Cancer-related information, support, services, and resources
- **Canadian Cancer Society**: **1-888-939-3333** (toll free in Canada) **416-961-7223** [cancer.ca](https://www.cancer.ca) Cancer-related information, support, services, and resources to improve the quality of life for cancer patients.



Think About Your Life - Living Well with Cancer

Think About Your Life started with four women who went on their own cancer journeys; two in the UK and two in the USA. The website materials and thinking tools aim to help those who are feeling out of control, helpless, or overwhelmed by the changes that a cancer has brought into their lives.

The *Think About Your Life* thinking tools are meant to help you regain control; to help you to think about what is happening, to bring together the support you need, and to look ahead.

You can use these thinking tools wherever you are on the cancer journey, from the initial discovery that something's not right, through treatment, to life after cancer.

How to Start Your *Thinking About Your Life* Journey

Materials and tools are divided into five stages in the cancer journey: discovery, diagnosis, treatment, end of treatment, and living with cancer.

In each stage, there are tools recommended for you to try – and suggestions for co-survivors as well.

For example, in the discovery stage, the following tools are listed, along with samples:

- **Good Day Bad Day.** If you want help figuring out how to cope while waiting for test results or to see the doctor
- **What's Working – Not Working.** If you are concerned about something, such as the approach your doctor is using, the tests you are undergoing, the frustration you are feeling.
- **Hopes and Fears.** If you want help thinking about what you are feeling, and to take some action or find support.

Other tools: One-page Profile, What's Working/Not Working, Communication Chart, Decision-making, Hopes and Fears, Matching Support, Dreams, Four Plus One Questions, and Good Health Support. The tools are simple – a few questions or categories – along with some guiding questions or comments.

We have provided two tools in this book – the One-page Profile and Good Day/Bad Day. You can find all their “Living Well with Cancer” materials, including tools and an extensive workbook, on their website at: thinkaboutyourlife.org/journeys/living-well-with-cancer

If you are interested in reading more of their materials or using their tools or workbook, you can create an account on their website quickly, and at no cost.

My One-page Profile Thinking Tool

The One-page Profile quickly tells people what matters most to you, and how they can best help.

Make a list for each question. The bulleted questions are meant to help you begin.

What do other people appreciate about me?

- What do other people appreciate, like or admire about you?
- This can be a hard one! What do people tell you when they compliment you?
- Are you brave? Funny? Smart? Good with your hands? A great cook? A problem solver?

What's important to me?

- What are the things you hold dear and make you who you are?
- What are your interests?
- How do you like to spend your free time?
- Who knows and loves you best?
- What do you absolutely not want to happen in your life?
- What qualities do you like the people around you to have?

How best to support me?

- In an ideal world, how would the people around you behave?
- What do people need to know to help you have better days, or to be at your best?
- What can people do to help you have better days, or to be at your best?
- If you're thinking about home life, what would make an ordinary day easier for you?
- If you're unwell, how can your family and friends help you?
- What would make a working day run more smoothly for you?

The form is a hand-drawn template with a black border. In the top-left corner, there is a small square box containing a silhouette of a person's head in profile, with the text "Your face here!" written inside. To the right of this box is a large rectangular area with a dashed border, labeled "What other people appreciate about me". Below the profile picture box is another large rectangular area with a dashed border, labeled "What is important to me". To the right of this area is a third large rectangular area with a dashed border, labeled "How best to support me?".

Good Day/Bad Day Thinking Tool

Whatever challenges you are facing, there's no doubt that some days will be harder to cope with than others. By looking at the elements of a good day you can find ways to make the toughest days go better. If you know why bad days are hard, and what can make them easier, you can take action. This tool is simply three columns – Good Day, Bad Day, and Next Steps - with guidance.

Think about a day (or part of a day) that was pretty good. What happened on this good day?

- What helps you cope?
- When do you smile?
- Who are you around?
- Who do you talk to (not talk to)?
- What do you do?
- What are your routines?
- Who do you see or do things with?
- Do you get exercise?
- What does that look like?
- What do you eat?
- What do you do for yourself?
- When you are home what do you do?
- What was a great morning like? Middle of the day? Evening?

Think about a day (or part of a day) that was pretty bad. What happened?

- At what points do things feel overwhelming?
- What routines didn't happen?
- What did you not get to do?
- Where did you have to go or not get to go?
- What did you do that you would rather not have done?
- Did you get enough sleep?
- Did you know when you woke up you were going to have a bad day?
- Did you not eat right?
- What was a bad morning like? Middle of day? Evening?
- Was there a particular thought that made you so unhappy?

Next Steps

This is where you look for things you can control. What is one step you can take towards making more good days? For example: I will link this information to my Facebook page, or email this to my sister so she will know what is going on, or call my doctor to get an appointment.

Message from the creators of “Think About Your Life”

We Put You at the Center

“We work with individuals, communities and organizations who want to find better ways of working and living. We always place people – not processes, theories or systems – at the center of what we do. This is called ‘person-centered thinking and planning’, but all it means is that we start with you. This is your life, and you should always be the one in control of it.

The thinking tools on the Think About Your Life website draw on our years of experience of working with people at times of major change or challenge in their life.

But they also draw deeply on our personal experience: we began this work because we have each lived with cancer – ourselves or as a co-survivor. We developed this website because we needed to use the person-centered thinking tools ourselves and wanted to share what we were trying and learning.

We pioneered the use of person-centered thinking tools with cancer survivors, and then developed them further with people who have long-term conditions, people at the end of their life, and people facing other life-changing events.”

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Thinking Tools and other materials used with permission of the Helen Sanderson Associates (HAS) for “Think About Your Life”.

Website: thinkaboutyourlife.org



Pharmacy Services

Roswell Park's pharmacists are experienced and knowledgeable with cancer care, and exclusively serve cancer patients. Cancer drugs can be hazardous if not taken properly and can have complex side effects. Our pharmacists will counsel you on the proper use of your medications.

Roswell Park Pharmacy - Main Hospital - <https://www.roswellpark.org/current-patients/pharmacy>

- ✓ Outpatient: Refill your prescriptions when you're here for your appointment.
- ✓ Inpatients: Concierge service can immediately fill your prescription(s) before you are discharged.
- ✓ Available: Oral chemotherapy, hard-to-find specialty drugs, common over-the-counter products.
- ✓ Free delivery service to local addresses. Free overnight shipping to all addresses.
- ✓ Personalized cancer-focused attention from your pharmacist. If you are taking oral chemotherapy, they will provide a courtesy call to remind you when your medication is almost due for a refill.
- ✓ Transferring prescriptions to Roswell Pharmacy: At your next visit, ask your doctor to send your prescriptions to Roswell's pharmacy electronically; we will have them ready before you leave. If you need a refill, we can contact your current pharmacy to request a refill transfer.

Location/Hours: First floor of the main hospital, next to the cafeteria. Hours: Monday - Friday: 9 a.m. - 6 p.m. and Saturdays: 9 a.m. - 1 p.m.

Contact: Phone: 716-845-8999 Fax: 716-845-8996 Email: RoswellParkPharmacy@RoswellPark.org

When pharmacy is open, calls will be answered by a pharmacy team member. After hours, please leave a message. If urgent, call Roswell's main number: **716-845-2300** or toll free: **1-800-ROSWELL**

Roswell Park Care Network's Medically Integrated Dispensary

Patients at some of Roswell Park's Care Network locations have a convenient option for many prescriptions through our medically integrated dispensary (MID). The dispensary offers many benefits such as convenience, access to specific oncology medications sooner, confirmation of benefits and assistance with high copay medications, and coordination of refills. Our pharmacist has direct line of communication with your doctor, allowing for faster responses to your questions. Dispensary staff will contact you, particularly when you start your medication, to see how you are doing and if you missed any doses.

Hours: Monday through Friday, 8 a.m. – 4 p.m.

Address: 199 Park Club Lane, Williamsville, NY 14221*

Phone Number: For more information, call: **716-634-3340 ext 5641**

* You may be able to pick up your prescription at the closest Roswell Park Care location: Northtowns, Southtowns, Jamestown, or Roswell Park Dermatology.

Taking the Lead

