

Patient Education

Quick Guide for Patients Receiving Chemotherapy



This packet is a resource for you. It has important information that can help you during chemotherapy treatment. There are also contact phone numbers for you. Please ask your nurse or healthcare team if you have any questions.



Stony Brook Cancer Center



Your Information

Name

First

Middle Initial

Last

Medical Conditions

Diagnosis

Healthcare Providers

Attending Oncologist

Phone #

Nurse Practitioner or Physician Assistant

Phone #

Nurse Navigator/Coordinator

Phone #



Stony Brook Cancer Center



Chemotherapy Treatment Plans



Follow-Up Appointments

<u> </u> / <u> </u> Date Time	<u> </u> / <u> </u> Date Time
<u> </u> / <u> </u> Date Time	<u> </u> / <u> </u> Date Time
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<u> </u> / <u> </u> Date Time	<u> </u> / <u> </u> Date Time

Please call (631) 638-1000 if you cannot keep your appointment(s).



Contacting Us

When should I call the office with a problem?

Call us as soon as the office opens, at 8:30 am. Please call as early as possible, so that we have enough time to schedule an appointment, if needed.

Call our department at _____.

Monday-Friday • 8:30 am to 5 pm

For after hours, holidays and weekends:

Majority of Patients: Call (631) 689-8333 and ask the Hospital Operator for the Hematology/Oncology Fellow On-Call.

Patients under the care of Urology Oncology: Call (631) 689-8333 and ask the Hospital Operator for the Urology Resident On-Call.

Patients under the care of Gynecologic Oncology: Call (631) 444-2989 and follow the instructions.

CALL US TO REPORT

- Bruising or bleeding not related to an injury
- Diarrhea or constipation
- Mouth sores or sore throat
- Mild difficulty breathing
- Nausea and vomiting
- New swelling of arm or leg
- Pain
- Rash or itchiness
- Other problems or questions

CALL US 24 HOURS-A-DAY TO REPORT

- Fever of 100.4° F (oral) or higher and/or shaking or chills
- Uncontrolled vomiting or diarrhea
- New onset of bleeding or difficulty breathing
- ANYTHING that you feel should not wait for office hours to begin

911

Call an ambulance and go to the nearest Emergency Room if the problem is LIFE THREATENING or you THINK it may be.



Stony Brook Cancer Center



Preparing for Your Appointment

What should I bring?

Tips on what to bring on your first day of infusion therapy:

- Infusion information folder.
- Wear comfortable clothing.
- If you have a port or catheter, please wear a loose-fitting shirt with a V-neck.
- Water.
- Snacks.
- Lunch (depending on the length of treatment).
- Cell phone.
- Your license or other form of identification and your insurance card.
- Book/magazine.



How can I learn more about chemotherapy?

We created an educational video for patients and families that is available for you to view at your convenience. This informative video provides information about managing the symptoms mentioned in this packet.

The video can be accessed with the following link: bit.ly/chemotherapyinfo

You may view the video on a mobile device with a camera by scanning this QR code:

In addition, please write down any questions you may have after watching this video, so that we have the opportunity to address your concerns as you begin this journey.





Stony Brook Cancer Center



Taking Care of Yourself

Your physical health and emotional well-being are extremely important. It is not unusual to experience some emotional changes during this time. Mood swings are common. It is helpful to let us know if you are having difficulty coping.

You do not have to go through it alone. We are always here to listen to your concerns. Your doctor or nurse can refer you to someone who can assist you. All of us experience things differently and we understand that.

In addition to your doctor and the oncology nurses, there are social workers and registered dietitians that are available for any questions or assistance you might need. Chaplain services can also be arranged.

Questions or notes to bring to your healthcare team:



Definitions of Words Related to Chemotherapy and Your Care

During the course of your treatments and visits to the clinic, you might hear some terms that you are not familiar with. We have written a short list of definitions below, but if you are ever unsure of something or need clarification, please ask. We want you to feel comfortable and safe while you are in our care.

Chemotherapy refers to drugs that interfere with the cancer cell's ability to divide and reproduce. One feature of cancer cells is that they divide and grow rapidly. Some drugs will kill resting cancer cells, and some drugs kill cancer cells during a certain phase of cell division. However, chemotherapy can also harm the good cells in the body that are rapidly dividing, which causes side effects. While these side effects are unpleasant, there are medications and interventions available to help manage those side effects throughout your treatment.

– *Examples include, but are not limited to: Adriamycin®, cisplatin and vincristine.*

Immunotherapy refers to drugs that interfere with the cancer cell's ability to divide and grow by either aiming for a target on the cancer cells' surface (receptor); blocking the cancer cells' ability to hide from your immune system; or stopping the tumor from making new blood vessels, causing it to starve. You may hear names such as 'biotherapy', 'monoclonal antibodies', 'targeted therapy', or 'precision medicine'. Not all patients with cancer are candidates for these treatments. Your oncologist will let you know if you will benefit from immunotherapy.

– *Examples include, but are not limited to: nivolumab, pembrolizumab and durvalumab.*

Immunosuppression is a condition when your body's ability to fight infection is not normal. This commonly happens after chemotherapy and/or radiation, but might also be related to your disease itself.



Definitions, cont.

CBC is the name of the blood test (Complete Blood Count) that we use to monitor the number of white blood cells, red blood cells and platelets in your blood. All of these cells may be affected by your cancer treatment or disease.

Neutropenia refers to a low neutrophil count, a specific type of white blood cell important for fighting infection. If the number of these cells is too low, you are at a higher risk of developing an infection. Your doctor or nurse will be able to tell what your neutrophil count is based on a blood test.

H&H (hemoglobin and hematocrit) refers to your red blood count. Red blood cells supply oxygen to your body. We look at these levels to determine if you may need a blood transfusion.

Platelets are the type of cell that helps your blood clot. Increased bruising, nosebleeds or bleeding gums might be a sign of platelets being low. Platelet transfusions may be needed.

Alopecia refers to hair loss. This is common in many chemotherapy regimens, but not all chemotherapy treatments cause this.

Antiemetics are medications given to prevent or treat nausea. There are many kinds available and sometimes you may need to try a different one.

– Examples include, but are not limited to: ondansetron (brand name: Zofran®), palonosetron (brand name: Aloxi®) and prochlorperazine (brand name: Compazine®).





General Instructions

- Take a shower or sponge bath daily with warm (not hot) water and mild soap. Do not share towels or washcloths with other members of your family.
- Wash your hands frequently, especially before and after preparing food or using the bathroom and any time you shake someone's hand.
- Maintain good oral hygiene. Brush your teeth after every meal and at bedtime with a soft toothbrush.
- Avoid close contact with people who have colds, the flu, or who have been recently vaccinated. Avoid crowds if you are neutropenic (low white blood cell count).
- Avoid swimming in oceans, lakes or public pools if you are neutropenic (low white blood cell count).
- Take your temperature if you feel hot, have a headache, have chills, are sweating, or if you are just not feeling well. Call your doctor if your temperature is greater than 100.4° (F).
- Call your doctor at the first sign of infection (See examples under Infection Prevention).
- Exercise, like walking, is fine and good for you, but do not push yourself to the point where you are out of breath.
- Use an electric razor for shaving if you have low platelet counts.
- Avoid blowing your nose forcefully; it may cause nosebleeds.
- During your treatment, there are no general dietary restrictions. Alcohol is usually not recommended, however, you may speak to your doctor about this. If your white blood cells are low, we may ask that you follow a special diet. You will receive special instructions if this happens.

Please tell your oncology team about all vitamins and herbal substances you are taking. They may interfere with your cancer treatment.





Notifying Your Doctor

Remember: CALL your doctor about the following symptoms or problems as soon as possible. Please do not feel uncomfortable about calling when you feel something is not right. The earlier you call with a problem, the sooner we can take care of it.

Take the following steps:

- Temperature greater than 100.4° F (oral temperature)
- Redness, swelling, drainage or tenderness around your catheter site, or any other wound site
- Pain, swelling or redness of your throat, eyes, ears, skin, joints, or abdomen (belly)
- Chills or sweating with or without fever
- New cough
- Shortness of breath
- Abnormal bleeding
- Mental status changes
- Diarrhea in large volumes or associated with crampy abdominal pain
- Uncontrolled nausea or vomiting
- Burning or pain upon urination, or bloody or cloudy urine
- Small blisters, like cold sores, near your mouth or any other part of your body
- Soreness or tenderness in or on your mouth or tongue
- Bleeding from your gums, nose, catheter site, etc.
- Bloody stools
- Skin changes (i.e., rash)





Infection Prevention

Chemotherapy and/or radiation will make you more prone to infections by decreasing your white blood cells. White blood cells evolve from stem cells, which are made in your bone marrow. Almost any part of your body can get an infection, including your mouth, skin, lungs, blood, urinary tract, rectum and reproductive tract. It is imperative to take precautions to prevent infection.

Take the following steps:

- Wash your hands often during the day. Be sure to wash them extra well before you eat and before and after you use the bathroom.
- Clean your rectal area gently but thoroughly after each bowel movement. If using baby wipes, be sure they do not have alcohol in them.
- Stay away from people who have diseases you can catch, such as a cold, the flu, measles or chickenpox. Avoid crowds if your white blood cells are low.
- Do not cut or tear the cuticles of your nails. Use cuticle cream and remover instead.
- Use an electric shaver instead of a razor to prevent breaks or cuts in your skin, especially when your platelet and white blood cell counts are low.
- Take a warm (not hot) shower or sponge bath every day. Pat your skin dry using a light touch. Don't rub.
- Use lotion or oil (new bottle) to soften and heal your skin if it becomes dry and cracked.
- Clean cuts and scrapes right away with warm water, soap and an antiseptic.
- Do not garden or clean up after animals without wearing gloves.
- Do not get any immunizations (shots) without first checking with your doctor.
- Avoid construction sites and home remodeling while you're susceptible to infection.



Infection Prevention, cont.

Even if you take precautions, it is possible that you may still get an infection. Be alert to the signs and symptoms that you might have. People with a suppressed immune system may not have obvious signs of infection. It is important to notice the slightest changes you may feel and notify your doctor. If you have a fever, do not take aspirin, Tylenol®, or any other medicine to bring your temperature down without first checking with your doctor. Always have a thermometer on hand.

The symptoms of infection may include:

- Fever over 100.4° F
- Chills and/or sweating with or without fever
- Loose stools
- Frequency or a burning feeling when you urinate
- Sore throat or mouth sores
- Unusual vaginal discharge or itching
- Redness, swelling or tenderness around a wound, your catheter or IV site, or any other skin surface
- Shortness of breath or cough



Reactions and Precautions

Nausea and Vomiting

Nausea and vomiting may be difficult to control. The best way to control your nausea is to take your antiemetic medication as prescribed *as soon as you notice nausea*. Sometimes, your doctor may prescribe medication around the clock, even if you are not nauseated. Different drugs work for different people, and you may need to use more than one drug to get relief. Do not give up. If you continue to have nausea and vomiting despite medication, notify your doctor right away! You may need intravenous medications and fluid replacement. If you are unable to purchase your nausea medications, please speak to your doctor.

Other good advice:

- Avoid big meals so your stomach will not feel full. Eat small meals throughout the day.
- Eat and drink slowly.
- Stay away from sweet, fried or fatty foods.
- Eat foods that are cold or at room temperature, so you will not be bothered by strong smells.
- If nausea is a problem in the morning, try eating dry foods like cereal, toast or crackers before getting up. (Do not try this if you have mouth or throat sores or if you are troubled by a lack of saliva.)
- Rest in a chair after eating, but do not lie flat for at least two hours.
- Breathe deeply and slowly when you feel nauseated.
- Distract yourself by chatting with friends or family members, listening to music, or watching a movie or TV show.

Fatigue/ Anemia

Your chemotherapy regimen may reduce your bone marrow's ability to make red blood cells, which carry oxygen to all parts of your body. When there are too few red blood cells, your body's tissues do not get enough oxygen. This condition is called anemia.

Anemia may make you feel tired and weak. You may have shortness of breath or feel dizzy. You may receive blood transfusions as needed to help combat this problem. Be sure to listen to your body and do what it is telling you. You will need more frequent rest periods and you will likely need help with more things than you are used to. Get plenty of rest and take naps during the day. When sitting or lying down, get up slowly. This will help to prevent dizziness.

Learn to adjust your schedule. Do your most important tasks during periods of higher energy.

Taking a daily walk (even a short one) helps to circulate your blood and increase your energy level.



Reactions and Precautions, cont.

Skin Changes and Precautions

Taking precautions to protect your skin is very important. Chemotherapy can make your skin more sensitive to the effects of the sun, which may cause sunburn and UV damage, especially between the peak hours of 10 am and 3 pm. Be sure to wear sunscreen with at least SPF 15 when outdoors. Do not forget to reapply sunscreen as directed. Wear sunglasses to protect your eyes. Hats and light clothing should be worn to protect sensitive areas. Lips also need protection and there are many products available, which contain sunscreen.

Some patients may develop *skin changes* during chemotherapy such as:

- **Facial Flushing:** Redness from the neck up the day after chemotherapy is most often caused by steroids given prior to your chemotherapy.
- **Rash:** There are some treatments where a rash is expected, but unless told otherwise, you should call to let your doctor know if you develop a rash.
- **Darkening of the skin** and/or fingernails is also a common side effect. This will return to normal when you complete chemotherapy.

Mouth Care for Mouth Sores (Mucositis)

A common side effect of chemotherapy is mouth sores (mucositis). Mucositis usually occurs when you become neutropenic (low white blood cell count). Good oral care is an absolute requirement. Below are instructions you should follow for oral care.

1. Gently clean your teeth and tongue with a soft toothbrush four to five times a day. With severe mucositis, mouth care should be increased to every two hours (while awake) with a sponge or cloth.
2. Rinse mouth for one minute after every meal and at bedtime, at least five times a day, with salt and baking soda mouth rinse. At home, mix one teaspoon of baking soda and one teaspoon of salt in eight ounces of warm water. *Avoid mouthwashes that contain alcohol.*
3. Apply lip moisturizer to prevent drying and cracking of the lips after mouth care and as needed.
4. Try Biotène® mouthwash and toothpaste for gentle cleaning and dry mouth. It is available over the counter at most local pharmacies.
5. Taste buds may be altered related to the chemotherapy. Salt and baking soda rinses noted above (#2) may help with this.
6. If your mouth hurts but you don't see any sores, rinse with salt and baking soda. If you see pustules or blisters in your mouth, call the doctor or nurse.

Reactions and Precautions, cont.

Diarrhea

Diarrhea is a common problem. It is usually due to chemotherapy and/or radiation. Notify your nurse or doctor about your diarrhea. It may be necessary to check your stool for infectious causes.

For improvement of your diarrhea, try these ideas:

- Eat smaller amounts of food, but eat more often.
- Avoid high-fiber foods, which can lead to diarrhea and cramping.

High-fiber foods include whole-grain breads and cereals, beans, popcorn, and fresh or raw fruits and vegetables.

Low-fiber foods include white bread, white rice or noodles, creamed cereals, ripe peeled bananas, canned or cooked fruit without skins, eggs, mashed or baked potatoes without the skin, pureed cooked vegetables, chicken or turkey (well done) without the skin, and fish (well done).

- Avoid coffee, tea and sweets. Stay away from fried, greasy or highly spiced foods, too. They are irritating and can cause diarrhea and cramping.
- Drink apple juice, water, weak tea, clear broth or ginger ale. Drink them slowly and make sure they are at room temperature. Let carbonated drinks lose their 'fizz' before you drink them.
- Avoid milk and milk products if they make your diarrhea worse.
- Have Imodium A-D® on hand. The generic version of this medication is called loperamide and costs less. Do not use this medication until instructed by your physician or nurse.

Constipation

Some people who receive chemotherapy become constipated because of the drugs they are taking. Constipation may also occur because of decreased activity or decreased oral intake. Tell your doctor if you have not had a bowel movement for more than a day or two. You may need to take a laxative or stool softener. Do not use these remedies unless you have checked with your doctor. Enemas are NOT permitted while your white blood cells and platelet counts are low.

You can also try these ideas to deal with constipation:

- Drink plenty of fluids to help loosen the bowels. Warm fluids work especially well.
- Eat a lot of high-fiber foods. High-fiber foods include bran, whole-wheat breads and cereals.
- Strenuous exercise is not suggested. However, you may walk outdoors or on a treadmill for as long as you can comfortably tolerate.
- Have a stool softener, such as docusate sodium, as well as a laxative such as milk of magnesia on hand.
- Speak to your doctor for a specific plan to follow regarding this problem.

Reactions and Precautions, cont.

Blood Clotting and Bleeding Problems

Chemotherapy and/or radiation therapy will affect your bone marrow's ability to make platelets, the blood cells that help stop bleeding by making your blood clot. If your blood does not have enough platelets, you may bleed or bruise more easily than usual, even from minor or no apparent injury.

Be sure to notify your nurse and doctor if you notice or have:

- Unexpected or unexplained bruising.
- Small red spots under the skin- petechiae, particularly noticeable on the lower legs.
- Black or bloody stools.
- Bleeding from your gums or nose.

Here are some ways to avoid problems when your platelet count is low:

- Do not take any medicine without first checking with your doctor or nurse. This includes aspirin or aspirin-free pain relievers.
- Don't drink alcoholic beverages.
- Use a very soft toothbrush to clean your teeth. Do not use dental floss or toothpicks.
- Avoid contact sports and other activities that might result in injury.

Muscle Aches and Pains

Muscle aches and pain are fairly common with certain chemotherapy regimens. Certain drugs may cause muscle and joint aches and pains (example: Neulasta® → bone pain). Ask your doctor if you can take Extra Strength Tylenol® or something else for relief.

Hair Loss

Hair loss is a common side effect of many (but not all) chemotherapy treatments. Hair dyes and chemicals should be avoided. Hair loss might be from the whole body or only a thinning in areas.

Ask your doctor what to expect and get a prescription for a wig prior to the start of your treatment, if recommended. Stony Brook Cancer Center has a program to assist you if your insurance does not cover the cost of a wig. There is an attached list of vendors who have been recommended by some of our previous patients. You might also want to consider trying a short haircut or other types of head coverings during treatment.

Your scalp may be extremely tender during this time, and your physician may okay the use of acetaminophen (Tylenol®) to manage this. *But check first.* Hair loss is usually temporary.



Resuming Your Activities

You may feel like getting back to an activity you did prior to being diagnosed or you may find that it takes time before you feel up to managing your normal schedule. Do not push yourself faster than you are able to go, and try not to become upset if your recovery takes longer than you would like. Your body needs time to recover from all that you have been through.

Your team will let you know when you can return to work, school or your normal daily routine. Much of this decision will have to do with your blood counts and level of fatigue; until they are high enough, you may have to stay at home to decrease your risk of bleeding, and most important, infection.



Sexuality

Regarding sexual activity, we recommend no intercourse or oral sex for three to seven days after chemotherapy. If you and your partner are going to engage in sexual activity, a barrier method (condom or dental dam) should be used on the day of chemotherapy and for one week afterward, to limit exposing your partner to the drugs you received. Otherwise, it is up to you, based on how you feel. These precautions are suggested to lower your risk of infection, bleeding and fatigue. You and your partner should practice careful hygiene, and you should make sure your partner does not have any signs of infection (including colds, draining sores or herpes). If you have questions or are having problems, for example, vaginal dryness or impotence, please speak to your doctor.

Contraception (prevention of pregnancy) is important as well. The use of a condom is strongly suggested. Sometimes chemotherapy treatment may cause temporary or permanent menopause (absent menstrual periods). However, some people may remain fertile and it is possible to become pregnant while undergoing cancer treatment. Pregnancy that happens during this time may cause birth defects in the embryo or fetus or may result in loss of the pregnancy (miscarriage). Please speak with your doctor about what other methods of birth control would be best for you during your cancer treatment.

Although you may resume sexual activity, you may find that you are not very interested. There are many reasons for lack of interest including fatigue, stress and changes in hormone levels. It is important to remember that, as with everything else, getting back to normal in terms of sex will take time.

The American Cancer Society has helpful information on managing many different cancer-related side effects, including fertility and sexual concerns.

Visit cancer.org/treatment/treatments-and-side-effects/physical-side-effects.html or contact their national office for copies at: (800) ACS-2345.





Relaxation Techniques

You can use a number of methods to cope with the stress of having cancer and its treatment. The techniques described here can help you relax. They can also help relieve nausea and vomiting that may occur with treatment. Try some of these methods to find the ones that work best for you.

Muscle tension and release. Lie down in a quiet room. Take a slow, deep breath. As you breathe in, tense a particular muscle or group of muscles. For example, you can squeeze your eyes shut, frown, clench your teeth, make a fist, or stiffen your arms or legs. Hold your breath and keep your muscles tense for a second or two. Then breathe out, release the tension, and let your body relax completely. Repeat the process with another muscle or muscle group.

You can also try a variation of this method, called “progressive relaxation.” Start with the toes of one foot, and working upward, progressively tense and relax all the muscles of one leg. Next, do the same with the other leg. Then tense and relax the rest of the muscle groups in your body, including those in your scalp. Remember to hold your breath while tensing your muscles and to breathe out when releasing the tension.

Rhythmic breathing. Get into a comfortable position and relax all of your muscles. If you keep your eyes open, focus on a distant object. If you close your eyes, imagine a peaceful scene or simply clear your mind and focus on your breathing.

Breathe in and out slowly and comfortably through your nose. If you like, you can keep the rhythm steady by saying to yourself, “In, one-two; Out, one-two.” Feel yourself relax and go limp each time you breathe out.

You can do this technique for just a few seconds or up to 10 minutes. End your rhythmic breathing by counting slowly and silently from one to three.

Imagery. Imagery is a way of daydreaming that uses all your senses. It is usually done with your eyes closed.

To begin, breathe slowly and feel yourself relax. Imagine a ball of healing energy — perhaps a white light — forming somewhere in your body. When you can “see” the ball of energy, imagine that as you breathe in you can blow the ball to any part of the body where you feel pain, tension, or discomfort such as nausea.

When you breathe out, picture the air moving the ball away from your body, taking with it any painful or uncomfortable feelings. (Be sure to breathe naturally; do not blow.) Continue to picture the ball moving toward you and away from you each time you breathe in and out. You may see the ball getting bigger and bigger as it takes away more and more tension and discomfort.

To end the imagery, count slowly to three, breathe in deeply, open your eyes, and say to yourself, “I feel alert and relaxed.”



Relaxation Techniques, cont.

Visualization. Visualization is a method that is similar to imagery. With visualization, you create an inner picture that represents your fight against cancer. Some people getting chemotherapy use images of rockets blasting away their cancer cells or of knights in armor battling their cancer cells.

Distraction. You use distraction any time an activity takes your mind off your worries or discomforts. Examples of distracting activities include watching TV, listening to the radio, reading or going to the movies. You can also work with your hands by doing needlework, puzzles, building models or painting. You may be surprised how comfortably time goes by.

The most important rule to remember with any chemotherapy or radiation therapy regimen is that:
Everyone is an individual.

No two people will have the same exact reaction or experience, even if they are receiving the same treatment. For this reason, it is important that you keep your treatment team informed of any changes, problems or concerns.

- Ask questions. (Write them as you think of them).
- Take notes.
- Bring a family member or a friend to act as an extra set of ears.

REMEMBER

We all have the same desired goal: working together to help you fight this disease by getting you through your treatments in the most comfortable and healthy way possible.

