



CANCER TREATMENT: BEFORE, DURING, AND AFTER

PATIENT AND FAMILY EDUCATION HANDBOOK



TABLE OF CONTENTS

A MESSAGE FROM A SURVIVOR	3
CANCER TREATMENT IS AN INDIVIDUAL EXPERIENCE	4
COMPREHENSIVE TREATMENT UNIT (CTU) CHECKLIST	5
FAQs: WHY DO I NEED TO WAIT FOR MY TREATMENT?	6-7
SIDE EFFECTS OF CHEMOTHERAPY	8
FEVER AND INFECTION	8-9
NAUSEA AND VOMITING	10
DIARRHEA OR CONSTIPATION	11
APPETITE AND TASTE CHANGES	12-13
MUCOSITIS	14
FATIGUE	15
CHEMO BRAIN	16
NEUROPATHY	17
HAIR LOSS	18
SCALP COOLING: PREVENTION OF HAIR LOSS DURING CHEMOTHERAPY	19-20
SEXUALITY AND CANCER	21-22
INFERTILITY	23
HOW TO PROTECT YOUR LOVED ONES	24
IMMUNOTHERAPY	25
ORAL THERAPY	26-29
SUPPORT SERVICES	30-31
MY CARE TEAM	32-33
ONCOLOGY CARE CLINIC	33
INSPIRING WORDS FROM A SURVIVOR	34
REFERENCES	35

A MESSAGE FROM A SURVIVOR

Dear New Patient,

When I was diagnosed with an early stage, but aggressive, form of breast cancer at the age of 46, the last thing I expected was that I was going to need chemotherapy and other infusions for a full year, as well as radiation and years of oral medication. My family and I were in shock, and we were not sure what to do next. A world-renowned oncologist at Sylvester was recommended to me. I went to see him and, immediately, he was able to help me focus on getting well. Fortunately (although it did not feel like it at the time), he explained that there had been studies that showed that treatment of this high-grade cancer with chemotherapy and another infusion medicine had a very high success rate. I have to say, before starting chemotherapy I was extremely frightened, but thanks to the guidance and kindness of the chemo nurses, the nurse navigator, my doctors, and the staff at Sylvester, I was able to get through it with less anxiety, fewer side effects, and less discomfort than I had expected.

Before starting treatment, I had many questions. What kind of chemo will I be receiving? What will the duration of the treatment be? What kinds of side effects will I experience? How can I best prepare for the chemo infusions? Should I go on a special diet? How could the treatment schedule be coordinated with my work and family commitments, if at all? The Sylvester team was there to answer all of these questions and more.

Looking back, I realize that there were a number of factors that helped me with the process:

Most importantly, my family and friends served as a team of caregivers, helping with everything from simple chores, to accompanying me to chemo treatments and doctor's visits, to preparing meals and just being there for me. It was especially important to have a family member with me for the early visits because they could take notes on the type of treatment, duration of treatment, etc.

Secondly, I learned to trust my doctor and nurses. Sylvester made this possible by being as transparent and supportive as possible. At each chemotherapy treatment and/or doctor's visit, the oncology team listened to me and my caregiver and provided information on the latest research, plus helpful tips. I learned that not every patient's experience is the same so it was okay to ask questions and talk about my unique and personal concerns.

I did have to become very organized, from keeping a working list of questions for the doctors and nurses, to prioritizing personal goals, and balancing family and work with realistic expectations.

Lastly, I found significant support through the guidance of the nutritionist and integrative medicine doctor at Sylvester. I recognized that rest, exercise, and good nutrition were key. Following their advice helped me recover faster after each treatment. My doctor recommended I walk every day, noting that it would help with fatigue so, even if I felt tired, I walked every day! I typically rested the day of, and two days after chemo, and then was able to continue working. I was able to attend many important family events.

I completed the chemotherapy regimen as planned, and I am going on two years of being cancer-free. I will be forever grateful to the amazing team at Sylvester Comprehensive Cancer Center.

- A Sylvester Survivor

CANCER TREATMENT IS AN INDIVIDUAL EXPERIENCE

Every person experiences chemotherapy, biotherapy, or immunotherapy treatment differently, both physically and emotionally. Depending on the type of cancer you have or your diagnosis, you may be receiving chemotherapy, biotherapy, immunotherapy, or a combination. Please be sure to ask your health care provider what kind of treatment you are receiving because side effects differ based on the type of treatment that will be administered. Fortunately, as the science of cancer treatment has advanced, so has the science of managing treatment side effects. Whatever you experience, remember there is no relationship between how the treatment makes you feel and whether you benefit from it. Many people feel fine for the first few hours following their infusion. Some reactions may occur. We have many ways to help you manage the side effects. Please let us know how you are feeling, so that we can address your concerns and help make you more comfortable. Your well-being is very important to us. There is a balance between the benefits of your treatment and the harm of possible side effects. Please tell your health care provider at any time if you feel that the harm is greater than the benefit.

BEFORE STARTING:

Before starting treatment, we suggest that you take care of some of your basic health needs. If time permits, have your teeth cleaned before, rather than while you are receiving treatment. If you need major dental work, try to postpone it until after treatment. If you need your teeth cleaned while receiving treatment, please let your doctor or nurse know before scheduling.

EMOTIONAL SUPPORT:

You can have a family member, friend, or support person accompany you to your treatment sessions. We recognize that cancer has an impact on you as a person, your family, and your loved ones. To varying degrees, all people with cancer struggle with the challenges of coping and adjusting to these life changes.

At Sylvester, we have a number of programs to support you through the process. Please refer to the support services section for further information.



COMPREHENSIVE TREATMENT UNIT (CTU) CHECKLIST

WHAT TO BRING WITH YOU THE DAY OF YOUR APPOINTMENT:

- A copy of your insurance card and a photo ID.
- Something warm and comfortable to wear to the CTU (jacket, pants, warm socks, a cozy blanket).
- Entertainment (books, magazines, crossword puzzles, board games, playing cards, tablet, laptop computer). We offer complimentary Wi-Fi for electronic devices.
- A charger for your electronic device.
- Headphones if you would like to listen to music/audio on your electronic device.
- We offer complimentary snacks and beverages, but if you would like to have something particular, you can bring it from home.
- If you are dependent on a feeding tube, bring your formula so that you do not miss a feeding.

REMINDERS:

- Did you fill all the medications required for treatment, such as nausea medications?
- Prior to treatment was fertility preservation discussed (if applicable)?
- Do you have follow up appointments with your physician and next appointments for treatment in the CTU?
- If applicable, were your molecular/genetic profile results reviewed prior to treatment?
- In case of an emergency, or to cancel or change an upcoming appointment, do you have the contact information for your providers, administrative assistant, and triage nurse?

FAQs: WHY DO I NEED TO WAIT FOR MY TREATMENT?

WHY DOES IT TAKE SO LONG TO PREPARE MY TREATMENT?

- All therapy preparation must be sterile, accurate, and timely.
- Your treatment must be sterile (germ and contaminant-free) to prevent you from getting an infection.
- Your treatment must be 100 percent accurate to how it is ordered. There is no room for error.
- Your treatment must be made in a timely manner by taking the least amount of time possible to produce a sterile and accurate product.

CAN MY TREATMENT BE ORDERED AND PREPARED PRIOR TO MY ARRIVAL IN CTU?

- Your provider may need to examine you and look at your laboratory results before he/she orders the treatment.
- Based on your examination, your provider may decide that you need a different dose, drug regimen, or perhaps receive no treatment at all.
- Some medications have short expiration times, so they cannot be prepared until you have arrived to CTU.

HOW MY TREATMENT IS PREPARED:

STEP 1:

- The oncologist orders your treatment.
- Physical exam, lab results, and your body's ability to handle the treatment are assessed.
- Drug, dose, method of administration, dates, and duration of treatment are determined.
- The CTU nurse reviews and releases the orders to the pharmacy for verification.

STEP 2:

- Two independent pharmacists review the orders.
- Each pharmacist reviews the drug regimen, lab results, dose, duration of administration, and any home medications.
- The pharmacist may need to call your oncologist to verify your lab results and obtain final approval.
- The pharmacist then verifies the orders in the computer system and prints a label that will attach to your treatment.

STEP 3:

- The pharmacist/technician initiates the preparation.
- The pharmacist reviews the lab results and checks the label for accuracy.
- The pharmacist/technician gathers and provides the medication vials, solutions, and any other components needed for the pharmacy technician to make your treatment.

STEP 4:

- The pharmacy technician reviews the label and confirms all components are correct.
- The pharmacy technician will calculate and measure the drug volume needed for the preparation.
- The pharmacy technician will add the drug volume to the IV solution and label the final product.
- Lastly, the pharmacist performs a final check.

STEP 5:

- The prepared treatment is packaged and delivered to the CTU nurse.
- The nurse administering your treatment confirms with a second nurse that your treatment label matches your doctor's order.
- Now your treatment is ready for you.

SPECIAL NOTES:

- It can take between 20-60 minutes to make one patient's treatment.
- Each pharmacist processes one order at a time to its completion.
- Please remember, timely does not mean fast. It means the least amount of time possible to ensure your treatment is carefully made. This ensures it is accurate, sterile, and safe for you and the health care personnel serving you.

For more information on treatment preparation and what to expect on your first day of treatment in our CTU, please watch our CTU orientation video by scanning the QR code below:



The next few pages review the most common related side effects and how to manage them. It is important to listen to your body and discuss any changes with your provider.

SIDE EFFECTS OF CHEMOTHERAPY

FEVER AND INFECTION

White blood cells (WBC) are the body's main defense against infection. Patients receiving chemotherapy are at risk for getting an infection when their white blood cell count is low. This condition, called neutropenia, is common after chemotherapy. For patients with this condition, any infection can become serious quickly. A fever may not send most people to the doctor's office. For a cancer patient, fever, along with weakness and pain, could signal an infection and may prompt a visit to the emergency room. When a person's immune system is weak because of cancer and its treatments, it is harder to recover, even from common illnesses. Some can become life-threatening. That is why patients need to report signs of infection, including fever, chills, abdominal pain, and a productive cough. If this happens, make sure you:

1. Call your provider immediately, especially if you have a temperature of 100.4° F or greater.

2. Go to an emergency room, if instructed by your provider.

3. Once in the emergency room, clearly indicate that you are undergoing cancer treatment.

Chemotherapy and fever may be related. Fever can be present in patients who are receiving chemotherapy treatments and biologic therapy as part of the "flu-like syndrome (FLS)." The fevers associated with FLS usually peak at 40°C or 104°F and often spike after severe chills. This is similar to sepsis (an infection in the blood). It is important that patients receiving biologic therapy be aware of the usual course of fever after treatment. Rather than waiting for infections to get out of control, work to prevent infection. There are three components to preventing infection:

1. Protect yourself from infection.

2. Recognize and report symptoms early.

3. Ask your provider about blood cell growth factor medications to reduce your risk of infection.

HOW TO PROTECT YOURSELF FROM INFECTION:

Bacteria causes most infections. These bacteria are normally found in your body, especially in your mouth, gastrointestinal (GI) tract, and on your skin. It is important to maintain good hygiene.

SELF-CARE:

- Wash your hands frequently, especially before eating, after using the bathroom, or after touching animals.
- Clean your rectal area thoroughly. Report symptoms of irritation or tenderness, or problems with hemorrhoids.
- Avoid rectal intercourse, tampons, douches, enemas, and rectal thermometers.
- Do not get any immunizations without checking with your health care provider first.
- Keep a thermometer at home and know how to take your temperature. Do not eat, drink, or smoke for 10 minutes before taking it.
- Call your health care provider as soon as possible if you develop a cough, sore throat, pain, or burning with urination.

SKIN CARE:

- Avoid getting cuts and skin wounds. Use an electric razor instead of blades to shave. Use care when using sharp instruments such as needles, knives, or other tools.
- Clean cuts and scrapes with soap and water, and apply an antiseptic.
- Do not squeeze or scratch pimples.

DENTAL CARE:

- Take good care of your mouth and gums.
- Always ask your health care provider before going to the dentist.

ENVIRONMENT:

- Stay away from people who are ill with colds, flu, measles, chicken pox, or other contagious illnesses. Stay away from children who have recently had “live virus” vaccines. These include chicken pox and oral polio vaccines.
- Avoid animal waste, litter boxes, birdcages, and fish tanks.
- Avoid standing water, as found in birdbaths, humidifiers, and flower vases.
- Wear gloves when gardening or cleaning up after others (especially small children).

FOOD:

- Do not eat raw fish, seafood, meat, or eggs.
- Do not share food with others, including family members.
- Wash all produce well before eating.
- Avoid eating out in restaurants when WBC counts are low, especially during peak hours when restaurants can be crowded.

NAUSEA AND VOMITING

Many cancer treatments can cause nausea and vomiting, making daily tasks difficult. If you take recommended medications before, during, and after treatment, nausea and vomiting can be reduced or even avoided. If you receive chemotherapy, nausea and vomiting can strike at any time. Some patients get nervous before receiving treatment and anticipate getting sick, which can actually make them ill.

Chemotherapy-induced nausea and vomiting (CINV) is one of the most feared and severe side effects of cancer treatment. Nausea and vomiting are classified as one of the following:

- **Anticipatory** - may be triggered when exposed to some stimuli, may be caused by prior CINV.
- **Acute** - occurring within 24 hours of chemotherapy administration.
- **Delayed** - occurring after 24 hours and lasting up to seven days.
- **Breakthrough** - occurring despite preventative medications.
- **Refractory** - occurring because of a failure of preventative and breakthrough medications to control the symptoms.

Chemotherapeutic regimens can be classified as having high, moderate, low, or minimal risk of nausea and vomiting.

With CINV, prevention is your best defense. Medications called anti-emetics or anti-nausea medications are used to prevent and treat nausea and vomiting due to chemotherapy. Many drugs are available. Doctors choose anti-nausea medications based on how likely each chemotherapy drug may cause nausea and vomiting. Patients may take as few as one to as many as four medications, depending on each situation. It is recommended to take the medication prior to chemotherapy treatment and continue with it after treatment as prescribed for two days around the clock while awake.

WHAT ADDITIONAL MEASURES CAN YOU TAKE TO PREVENT NAUSEA AND VOMITING?

- Before chemotherapy treatment, eat a small, light meal. Most patients do better if they have something in their stomach.
- Eat what sounds good to you or what you want. Generally, starches such as rice, bread, potatoes, hot cereals, and puddings are well tolerated.
- Do not skip meals. An empty stomach may worsen nausea symptoms.
- It is best to avoid foods that are sweet, fried, or fatty.
- Avoid unpleasant or unappealing smells. Foods that are cold or room temperature, rather than cooked, may give off less bothersome odors.
- Drink plenty of fluids. Herbal teas, water, sports drinks, and diluted juices are recommended.
- Separate solids from liquids to reduce stomach volume. If you've eaten, wait 45 minutes to an hour before drinking. If you have had a drink, wait 45 minutes to an hour before eating.
- Freeze meals so that you do not have to cook. Ask family and friends to help with food preparation, especially after chemotherapy treatment when patients are most likely to feel nauseous.
- Schedule an appointment with a dietitian for more practical tips on dealing with nausea and the best diet to follow.

DIARRHEA OR CONSTIPATION

Diarrhea is a common side effect that results from receiving chemotherapy. If you are having greater than four loose stools a day above your usual daily bowel movements, please call your health care provider. If left untreated, diarrhea can lead to severe dehydration and hospitalization. You can also consult with a dietitian for dietary management of diarrhea. Consult with your health care provider before taking any anti-diarrheal medication. Report immediately any fever, excessive thirst, dizziness, palpitations, severe abdominal cramping, or diarrhea that continues after taking anti-diarrheal medication. Constipation can occur due to actual cancer diagnosis, chemotherapy, dehydration, anti-nausea medications, and/or frequent use of pain medications for cancer-related pain. If you have not passed a regular bowel movement in three days, call your provider to discuss if starting a bowel regimen is appropriate.

- For maintaining regular bowel movements consider a bulking agent such as Miralax® or Metamucil® mixed with water.
- Maintain adequate hydration, drinking eight to 10, eight-ounce glasses of fluid per day.
- Regular exercise as tolerated can encourage an increase in gastric movement and release.
- Increase fiber intake to 25-30 grams a day. Foods high in fiber include spinach, broccoli, slow-cooked oatmeal, flax meal, prunes, pears, bran meal, beans, and lentils. For a more extensive list, consult with a dietitian.
- Drinking warm liquids such as warm prune juice, tea, or coffee can also help stimulate a bowel movement.
- For bowel evacuation, consider taking a stimulant laxative such as Bisacodyl® or Senna®, both of which can be purchased over the counter.
- Magnesium citrate can be taken for immediate evacuation.
- Suppositories should be **avoided** unless instructed by your provider.

If instructed by your provider, begin taking anti-diarrheal medication such as Imodium®. Imodium® should be taken as follows: 4 mg initial dose, then 2 mg every two hours until relief. Stop Imodium® after 12 hours without an episode of diarrhea.

Maintain adequate fluid hydration, eight to 10 glasses per day. Pedialyte® or sports drinks such as Gatorade® provide additional electrolytes that may have been depleted.

Limit dairy intake and increase foods that are low in soluble fiber such as rice, white toast, and mashed potatoes.

If rectal area becomes irritated, clean area with mild soap, and water after each bowel movement. You can also apply a barrier ointment.

Warm sitz baths may also further aide in relieving irritation.

APPETITE AND TASTE CHANGES

During chemotherapy, you may experience appetite changes and a high sensitivity to odors. It is not unusual to experience these changes the first few days or a week following chemotherapy. A poor appetite can be caused by a changed sense of taste or smell, feeling full, tumor size, dehydration, or the side effects of treatment. The condition can be made worse by many things, such as trouble swallowing, depression, pain, nausea, or vomiting.

As you feel better, your appetite will improve. You may find that you can tolerate only certain foods. We encourage you to eat what appeals to you during this time and to drink enough fluids. Aim to drink eight to 10, eight-ounce glasses per day or more if you have a fever or diarrhea.



PRACTICAL TIPS TO APPETITE CHANGES:

- Set meal times and routines.
- Try new foods to keep up your interest in food.
- Eat a little, even if you are not hungry. It may help to eat five or six small meals each day, instead of three large meals.
- Eat with family or friends, or watch television while you eat.
- Choose foods that are high in calories and protein.
- If food tastes like metal, consider eating with plastic forks or spoons.
- Be active which may help you feel hungrier.
- Drink liquids: Getting enough to drink is important, but do not fill up on liquids during meals. Drink milkshakes or soups that are easy to swallow.
- Keep track of how much you eat and drink each day.
- Remember it is important to eat well to help your body stay strong.

We recommend a balanced diet focused on high fiber and low fat (for example: lean proteins such as chicken, turkey and fish, and fruits and vegetables). Avoid excess soy and flaxseed products. Supplements or vitamins such as antioxidants (vitamins A, E, C, CoQ 10) are not recommended unless you have discussed them with your health care provider first. Contact our registered dietitian for more details about your diet while on your anti-cancer treatment.

TASTE CHANGES:

Taste changes are common during chemotherapy. The exact reason for taste changes is not clear. It is believed this can be a result of the damage to the cells in the oral cavity, which are especially sensitive to chemotherapy. Loss or change in taste can occur purely from the association of an experience of nausea and vomiting with the treatment. About 50 percent of patients getting chemotherapy experience taste changes. Taste changes may occur during therapy and last for hours, days, weeks, or even months after chemotherapy.

Drugs most commonly associated with taste changes include carboplatin, cisplatin, cyclophosphamide, dacarbazine, dactinomycin, doxorubicin, 5-fluorouracil, levamisole, mechlorethamine, methotrexate, paclitaxel, and vincristine. Some drugs also produce a metal taste during the actual intravenous infusion. These include nitrogen mustard, vincristine, cisplatin, and cyclophosphamide.

PRACTICAL TIPS TO IMPROVE TASTE:

- Maintain good oral hygiene. Brush your teeth before and after each meal.
- Choose and prepare foods that look and smell good to you. Eat small and frequent meals.
- Use plastic utensils if food tastes like metal.
- Eat mints (or sugar-free mints), chew gum (or sugar-free gum), or chew ice to hide the bitter or metallic taste.
- Substitute poultry, eggs, fish, peanut butter, beans, and dairy products for red meats.
- Marinate meats in sweet fruit juices, wines, salad dressing, barbeque sauce, or sweet and sour sauces.
- Flavor foods with herbs, spices, sugar, lemon, and tasty sauces.
- Chilled or frozen food may be more acceptable than warm or hot food except for patients receiving oxaliplatin.
- Try tart foods such as oranges or lemonade (this may be painful if mouth sores are present).
- Avoid cigarette smoking; eliminate bad odors; eat in pleasant surroundings to help in managing taste changes.
- Avoid places where food is cooked, such as the kitchen at dinnertime.



There is no one magic solution for taste changes that suits everyone. Finding foods that taste appealing may be a process of trial and error. Some people who experience taste changes avoid their favorite foods to prevent the possibility of spoiling them for the future.

MUCOSITIS

Chemotherapy causes damage to the cells lining the mouth and esophagus. Mouth sores are small ulcerations that usually appear as white patches in the mouth. Sometimes the patches can appear red or bleed. Typically, the areas affected are the tongue, gums, roof, or floor of the mouth. They can be painful and cause difficulty eating or drinking. The mouth sores can appear a few days after initiating chemotherapy and take two to four weeks to heal. If you are experiencing increased discomfort or inability to eat or drink, please contact your health care provider. They may be able to order prescription medication to assist with the discomfort. Eat good sources of protein, which may help build and repair tissue that has been injured. Protein can speed up the healing process of mouth sores.



PRACTICAL TIPS:

- Use a soft bristle brush to clean your teeth.
- Avoid mouth washes that contain alcohol.
- Increase fluid intake.
- Eat chilled foods.
- Rinse your mouth three to four times daily with the following solution:
 - Mix one teaspoon of baking soda with two cups of water.
- Eat soft bland foods.
- Contact your provider immediately if experiencing a temperature above 100.4 ° F or 38 ° C.

FATIGUE

Fatigue is being tired physically, mentally, and emotionally. It means having less energy to do the things you need or want to do. The fatigue that comes with cancer, called cancer-related fatigue, is different from the fatigue of daily life. Every day, normal fatigue usually does not last long. It often gets better when you rest. Cancer-related fatigue is worse and it causes more distress. People describe it as feeling weak, listless, drained, or “washed out.” Some may feel too tired to eat, walk to the bathroom, or even use the TV remote. It can be hard to think, as well as move your body. Rest does not make it go away, and just a little activity can be exhausting. For some people, this kind of fatigue causes more distress than pain, nausea, vomiting, or depression.

Fatigue may be from therapy, anemia, depression, pain, or certain medicines. Having trouble sleeping can also make you feel tired. It is very important to prioritize your daily activities as there will be times when you feel more tired than normal.

PRACTICAL TIPS TO DECREASE FATIGUE:

- Let others help you and do activities that are most important first.
- If you are able to, take time off from your job or work fewer hours.
- Rest when you feel tired and try to take short naps that are one hour or less during the day.
- Make a bedtime routine. Bathing or listening to music before you go to sleep may help you relax.
- Try to sleep seven to eight hours each night. Avoid caffeine in fluids (such as coffee, tea, energy drinks, or soda), medicines (such as headache remedies), or even in foods (such as chocolate) for at least eight hours before bed can help.
- Make healthy foods when you feel well. Freeze them to eat later. Eating helps you keep up your strength.
- Some people find it easier to eat five or six small meals or healthy snacks instead of three big meals. Drink plenty of water and juices. Get enough protein and calories to help your body heal.
- **Stay Active:**
 - Try to maintain daily exercise such as walking, swimming, biking, or similar activities. Even 15-30 minutes a day can help give you energy. Other activities such as yoga, stretching, and Tai Chi may be helpful.
- **Reduce Stress:**
 - Having cancer is stressful and cancer treatment can cause even more stress. Feeling tired has been linked to depression and anxiety.
 - Consider joining a support group. Sharing your feelings with others can help ease the burden of fatigue.
 - You can also learn coping tips from others by talking about your situation.
 - Mental health counseling, stress management training, and relaxation exercises are some ways you can learn to improve the feelings related to fatigue and help overcome the tiredness you feel.
- **Distraction:**
 - Sometimes feeling tired can become discouraging and frustrating. You may notice it becomes all you think about. Try to distract yourself with other things, such as listening to music, having relaxing visits with friends or family, or reading a book. These things can give you an escape from your fatigue without using up too much energy.
- It is important to tell your doctor or nurse if you are not able to do your normal activities, or if you are still very tired, even after resting or sleeping.

CHEMO BRAIN

Chemo brain is a term used to describe a cloudiness, brain fog or mental change that can occur before, during, or after cancer treatment. The exact cause is not known but can occur anytime when you have cancer and can cause short-term, long-term, or delayed mental changes. Your provider may refer to chemo brain as a cognitive change, which means the way your brain communicates, thinks, solve problems, and remembers.

You may want to ask your provider team if you are at risk for chemo brain based on your cancer and treatment, and when you would anticipate noticing any change. If you experience chemo brain, you might find it hard to perform usual activities like work, school, or social activities. It is important to talk to your provider team if you are experiencing mental changes to see what treatments or activities can help manage chemo brain.

EXAMPLES OF WHAT YOU MAY EXPERIENCE WITH CHEMO BRAIN:

- Forgetting things that you usually have no trouble remembering
- Difficulty in concentrating or finding hard to focus
- Trouble remembering details like names or phone numbers
- Difficulty in learning new things
- Trouble multi-tasking
- You take longer to finish things (slower thinking and processing)

ACTIVITIES TO HELP COPE WITH CHEMO BRAIN AND HELP SHARPEN YOUR MENTAL ABILITIES:

- Exercising improves your thinking and ability to focus
- Meditating can help increase your focus and awareness
- Keeping a detailed daily planner, notebook, or reminder notes
- Performing the most demanding tasks of your day when you feel the most energy
- Brain exercises such as word puzzles
- Do regular physical activity to keep moving. This helps you feel more alert, improve your mood, and feel less tired
- Keeping the same daily schedule
- Trying not to multi-task but focusing on one task at a time
- Avoiding alcohol or other agents that can change your mental state and sleep patterns
- Keeping a dairy to write down when you notice a memory problem or mental change
- Talking about your chemo brain with your family, friend, and cancer team

Cognitive rehabilitation includes activities to help improve brain function such as learning how the brain works, and how to take in new information. Talk to your provider team if cognitive rehabilitation is an option.

NEUROPATHY

Peripheral neuropathy can be described as a decreased sensation, numbness, or tingling to the nerve endings. It occurs most commonly in the fingers, feet, and/or toes. This is a result of nerve injury due to chemotherapy. It is usually reversible after treatment is completed.

- If neuropathy becomes painful or interferes with daily activities such as inability to button clothes, pick up utensils, or walking, inform your provider immediately. They may be able to prescribe medication such as gabapentin or amitriptyline to help alleviate symptoms.
- Due to decreased sensation, avoid extreme hot or cold temperatures.
- Routinely inspect arms and legs for cuts or abrasions.
- Routine exercise and increased physical activity have also been shown to improve symptoms, along with acupuncture.
- Assure safety parameters are in place at home.



HAIR LOSS

Most patients express concern regarding hair loss while undergoing chemotherapy treatment. It is normal to feel upset or concerned about losing your hair. It is important to remember that hair loss is typically temporary. Several weeks after completion of your treatment, the hair cells recover and the process of hair growth will begin.

WHY DOES IT HAPPEN?

Hair follicles grow at a rapid rate. Chemotherapy drugs attack rapidly growing cells thus causing hair loss. Not all chemotherapy regimens will cause hair loss. It is important that you speak with your physician or treating provider to discuss your treatment regimen. They can explain what to expect. Take the opportunity to address any concerns you may have about experiencing hair loss. If you are considering a wig, your health insurance may pay for it. You can request a prescription from your provider for a “cranial prosthesis” (i.e., wig) to assist with coverage. Sylvester offers wigs to patients experiencing hair loss. Please contact the Cancer Support Services Center for further information.

WHEN DOES IT OCCUR?

Hair loss typically occurs two to four weeks after initiating chemotherapy treatment. Each patient may experience hair loss differently. Some patients' hair loss is gradual while others is more quickly. There are approved therapies to assist with preventing hair loss such as scalp cooling cap. Discuss with your health care provider if this modality may assist you during your treatment.

PRACTICAL TIPS:

Be gentle with your hair after starting treatment. Avoid harsh dyes, perms, combing, or frequent washing. Comb hair with wide tooth comb.



If interested, select a head covering in advance such as a wig, scarf, or hat. If you are concerned about losing your hair, you may choose to cut your hair short or shave your hair before the hair falls out.



Your scalp may become irritated during treatment from exposure to sunlight or cold. Utilizing a head covering can lessen irritation. Also, protect your scalp with sunscreen if you choose to not wear a head cover.



SCALP COOLING: PREVENTION OF HAIR LOSS DURING CHEMOTHERAPY

WHAT IS SCALP COOLING?

Scalp cooling is intended to prevent hair loss while you are getting chemotherapy to treat certain tumors. Scalp cooling involves the use of a cold cap that is cooled to very cold temperatures. During each chemotherapy session, the cap is worn on your head before, during, and after your chemotherapy infusion.

Scalp cooling is not a universal intervention during chemotherapy. Talk to your provider to determine if scalp cooling therapy is appropriate with your current chemotherapy plan.

HOW DOES IT WORK?

During scalp cooling, the cold temperature tightens or constricts blood vessels in the scalp. This constriction is thought to reduce the amount of chemotherapy that reaches the cells of the hair follicles. The cold also decreases the activity of the hair follicles and makes them less attractive to chemotherapy, which targets rapidly dividing cells. This could reduce the effect of chemotherapy on the follicle cells, and, as a result, prevent or reduce hair loss from the scalp.

HOW IS SCALP COOLING DONE?

There are currently two approaches for scalp cooling available: automated systems that circulate coolant through cooling caps and manual cooling with frozen cold caps during which ice is placed in the cap to cool the scalp.

All caps have to be frozen ahead of time and brought to your chemotherapy appointment in a portable cooler with dry ice if a freezer is not available at your infusion center where treatment will be provided. Cold caps need to maintain a consistent cold temperature throughout, therefore, you will need multiple frozen caps in order to replace them with a new one approximately every 30 minutes.

Penguin™, Chemo Cold Caps™, and ElastoGel™ are some cold cap brand names. For more information visit the websites below:

- **Chemo Cold Caps™** - www.chemocoldcaps.com
- **Penguin™ Cold Caps** - www.penguincoldcaps.com
- **ElastoGel** - <https://cancer.livebetterwith.com/>

Automated cooling systems use a portable cooling unit that circulates a coolant in a flexible cap so that temperature is maintained within a narrow range. The cap only has to be fitted once and does not need to be changed during chemotherapy. At this time, the DigniCap™ and Paxman™ scalp cooling system have been cleared by the U.S. Food and Drug Administration (FDA). Here at Sylvester, we offer the DigniCap™ scalp cooling system. If you are interested in using DigniCap™, talk with your health care provider before your first chemotherapy treatment. For more information, visit the website below:

- **DigniCap™** - www.dignicap.com/patients

HOW LONG DOES SCALP COOLING TAKE DURING TREATMENT?

Regardless of the specific device that is used, cooling is started approximately 30 minutes before the chemotherapy infusion starts. Cooling is maintained for a period of time after the end of the chemotherapy infusion, generally between 90-120 minutes depending on the specific chemotherapy used. If you're using frozen caps, you can return home with your cold cap on to finish your cooling.

HOW MUCH DOES SCALP COOLING COST?

The cost of scalp cooling varies depending on the type of scalp cooling system you use and the number of chemotherapy treatments you will be having. Most insurance companies do not cover the cost of scalp cooling at this time.

There is some financial support available for scalp cooling offered from the organization "HairToStay." Please visit their website for more information at www.hairtostay.org/our-impact/

SEXUALITY AND CANCER

Sexuality is a part of our everyday life, but it is more than just the act of sex or reproduction. Sexuality includes our need for closeness, intimacy, caring, and pleasure. It also includes our sex drive, sexual identity, and sexual preferences. Cancer and its treatment can affect sexuality in a variety of ways. Even though the causes may be different (surgery, chemotherapy, hormone treatment, or radiation), the resulting changes are often similar. The most common sexual change for cancer patients is an overall loss of desire. For men, due to treatment-related side effects and/or other medical conditions, erection problems can occur. Women may experience vaginal dryness and pain with sexual activity. Men and women may have difficulty achieving an orgasm. Taking time and having patience for stimulation may increase the chances of having an orgasm. It is important to remember that these side effects will often improve after the completion of treatment.



COPING WITH SEXUAL CHANGES:

LOSS OF DESIRE:

- Communicate your feelings with your significant other. Make sure that you talk about your feelings instead of thinking “it will all get better with time.” Sexual changes are common during cancer treatment and communication is of high importance.
- Make time and set the stage for sexual activity (i.e., candles, music).
- Take pain or anti-nausea medication in a timely manner to promote comfort during sexual activities.
- You do not need to perform the act of intercourse in order to enjoy a fulfilling sexual relationship. Explore alternative methods of intimacy such as kissing, hugging, and non-genital touching/caressing. This may be just as effective for you and your partner.
- Rest before initiating sexual activity to minimize fatigue during and afterward.
- If you experience discomfort during sexual activities, use alternative positions such as lying side-by-side, with the man behind, having the woman on top, or elevating the head of the bed.

VAGINAL DRYNESS/PAIN:

- Pain during sex can occur after gynecologic surgery or radiation therapy to the pelvis or vagina. These treatments can shorten or narrow the vagina. To help prevent or alleviate symptoms use a vaginal dilator or have intercourse at least 3 times a week once cleared by your provider after surgery or radiation. Do not initiate any intervention, such as hormonal therapy until discussed with your health care provider.
- In some women who have undergone cancer treatment, the cause of vaginal dryness is hormonal changes. Chemotherapy can damage your ovaries so that they no longer produce estrogen and progesterone. Decreased amounts of estrogen also leads to a thinner, less elastic and more fragile vaginal lining. To help relieve symptoms, try a vaginal moisturizer, such as Replens[®], which can help the vaginal walls stay moisturized. Use moisturizers two to three days a week at night right before going to bed. Also, use moisturizers regardless of sexual activity to prevent further vaginal thinning or dryness. During sexual activity, one can also use a lubricant that is water-based (not hormone-based) such as Astroglide[®], Moist Again[®], or K-Y[®] Liquid prior to intercourse or dilator use.
- Avoid using anything that could be irritating such as lotions, deodorants, perfumes, harsh deodorant soaps, or douches in the vaginal area.
- Wear cotton underwear.

ERECTILE DYSFUNCTION:

- Discuss your concerns with your provider. Your provider can determine which treatment is appropriate for you and the likelihood you will benefit from a specific treatment.
- It is important to communicate openly with your partner.
- Some cancer treatments and drugs for other medical conditions (i.e. drugs to treat diabetes and heart disease) can impact your ability to have and maintain an erection. Discuss these concerns with a health care provider.
- Sildenafil (Viagra[®]), an oral medication, is currently the first-line therapy for erectile dysfunction.
- If not eligible for oral medication, or not responding to treatment, there are other options such as vacuum devices and penile prostheses.
- Maintain good general health through diet and exercise.
- Avoid alcohol.

INFERTILITY

WHAT IS INFERTILITY?

Some types of chemotherapy can cause infertility. For a woman, this means that you may not be able to get pregnant. For a man, this means you may not be able to get a woman pregnant.



WHY DOES IT OCCUR?

In women, chemotherapy may damage the ovaries. This damage can lower the number of healthy eggs in the ovaries. It can also lower the hormones produced by them. The drop in hormones can lead to early menopause. Early menopause and fewer healthy eggs can cause infertility. In men, chemotherapy may damage sperm cells, which grow and divide quickly. Infertility may occur because chemotherapy can lower the number of sperm, cause sperm to move slower, or other types of damage. Whether or not you become infertile depends on the type of chemotherapy you get, your age, and whether you have other health problems. Infertility can last the rest of your life.

MANAGEMENT:

Before you start chemotherapy, it is important to let your health care team know if you want children. Here are some specific questions you could ask during your meeting:

- Will my treatment affect my ability to have children in the future?
- Are there steps I can take before beginning treatment to preserve my fertility?
- What are the options available if I decide I want to have children in the future? Will my treatment affect that ability?
- How long after treatment should I wait before trying to get pregnant?
 - Women are often advised not to get pregnant within the first six months after chemotherapy because the medicine may have damaged the eggs that were maturing during treatment. If a damaged egg is fertilized, the embryo could miscarry or develop into a baby with a genetic problem.
- Is it safe for me to delay my cancer treatment to preserve my fertility?
- Will I be able to carry a pregnancy safely after treatment?

HOW TO PROTECT YOUR LOVED ONES

HOW TO PREVENT CHEMOTHERAPY EXPOSURE FOR CAREGIVERS AT HOME

When a patient is given chemotherapy, the medicine is present in body fluids (urine, stool, vomit, vaginal fluid, and semen) for 48-72 hours after the treatment ends. If you or a family member are currently receiving chemotherapy, whether in the clinic or at home, it is recommended that precautions be followed in order to keep household members safe:

- Family members should use separate toilets for 48 hours after chemotherapy administration to reduce risk of contact with contaminated body waste. In households with only one bathroom, keep disinfecting sanitizing wipes near toilet, clean toilet seat and rim after use, and flush twice after use. Wiping removes chemotherapy residue from surfaces. After toileting and cleaning, patients should wash their hands with soap and water before touching other surface items. At the end of 48 hours, the toilet and bathroom floor should be cleaned.
- If a bedpan, commode, or urinal is used, the caregiver should wear double gloves when emptying it. Rinse it well with water and wash with soap and water at least once per day. The same applies to basins used for vomiting.
- Wash clothing and linen as usual unless it is soiled with chemotherapy or body fluids. Use gloves and immediately put the soiled laundry in the washer separate from other laundry. If you don't have a washer available at the time, put laundry in a sealed plastic bag until it can be washed.
- If using throw-away adult diapers, underwear, or sanitary pads, seal them in two plastic bags and throw them away with your regular trash.
- If chemotherapy is spilled on skin, irritation or rash may occur. Wash the area thoroughly with soap and water. If redness lasts more than an hour, call the doctor's office. You can avoid contact with skin by wearing gloves when handling chemotherapy, equipment, or waste.
- For spills on the floor or in the home environment (not on your skin), your CTU nurse will supply you with a chemotherapy spill kit. Follow the instructions on the bag.
- All cartridges, bags, bottles, or tubing that contain chemotherapy must be disposed of in the supplied needle disposal box.
- Keep all chemotherapy medications, equipment, waste, needle boxes, etc. out of reach of children and pets.
- Caregivers who are pregnant, breast-feeding, or children should not handle any chemotherapy medications or waste products.
- Use a barrier protection (condom) during sexual activity to reduce your partner's exposure to chemotherapy agents.

IMMUNOTHERAPY

Immunotherapy refers to treatments that activate your body's immune system to fight cancer. The type of immunotherapy you receive depends on a variety of factors including cancer type and gene expression or mutation. Immunotherapy targets specific receptors that are present on the surface of your cancer cells and signals the immune system to destroy them. It is because of this specificity that immunotherapy does not have the typical side effects of chemotherapy such as nausea, vomiting, hair loss, anemia, mucositis, etc. There are other side effects that you must be aware of. Immunotherapy can send your immune system into overdrive which can cause inflammation in other parts of your body.

PULMONARY

Notify provider if you experience a new, persistent cough that is not going away or sudden shortness of breath.

GASTROINTESTINAL

Notify provider if you experience an increase in bowel movements, watery diarrhea, sudden abdominal pain, or if there's blood or mucus present in your stool.

RENAL

Notify provider if you experience a decrease in urine output, urine becomes dark, or if blood is present.

HEPATIC

Notify provider if you experience pain to your right abdomen, yellowing to the whites of your eyes, or dark-colored urine.

ENDOCRINE

Notify provider if you experience extreme fatigue, weight loss or gain, increased thirst, increased urine output, hair loss, feeling cold, or hot flashes.

SKIN

Notify provider if you experience a new rash.

ORAL THERAPY

An oral cancer drug is any medication taken by mouth to treat cancer. It can be a tablet, liquid, or capsule. These cancer drugs are sometimes referred to as oral chemotherapy. Oral cancer drugs can be broken down into three main types: one is cytotoxic or what is commonly referred to as chemotherapy or chemo, the other two are targeted therapies and hormonal agents.

These drugs are not just ordinary pills. They are powerful medications. Oral cancer drugs require special handling and it's important that you understand your medications so you can follow your treatment plan, manage any side effects, and report them to your health care provider when necessary. We want to help you learn about your oral cancer drugs so that you can get the most out of your treatment while keeping yourself and your loved ones safe.

HERE ARE SOME IMPORTANT THINGS YOU SHOULD KNOW ABOUT YOUR MEDICATION:

The time you should take it and how often.

How many days or months you may need to continue taking your medications.

What to do if you miss a dose or take too much.

The name and spelling of your drug.

The reason you are taking it.

Whether to take it with or without food or water.

Foods, drinks, or activities that should be avoided while taking medication.

Whether there are any other drugs, prescriptions, or over the counter medications that should be avoided.

It is important that you keep in touch with your health care team and ask them any questions you have about your medication or treatment plan. Every time you start a new medication or get a refill from the pharmacy, you should double-check your name and the name of the drug. You should always read the Food and Drug Administration insert that comes with your cancer medication. It will tell you about any possible food or drug interactions.

FOLLOWING YOUR TREATMENT PLAN:

It is important to take your medications exactly as prescribed. Not taking them properly can cause side effects and could affect how well the drug works. Making a plan and establishing a routine often helps people keep on track.

TIPS FOR REMEMBERING TO TAKE YOUR MEDICATION:

- There are many tools to help you, from smartphone applications (apps) to diaries. It does not matter what you use as long as you use it consistently.
- If you have a smartphone or tablet, go to the app store and search for pill reminders. You will see a large list of apps. See which one will work best for you. Look for one that can be personalized to your lifestyle and is easy to use. Some apps have an actual picture of the drug you are taking and will send you reminders to take your medication.
- Electronic medication reminders are also available. This may be a pillbox with alarms to remind you when it is time to take your medication.
- If you do not want to deal with computers or electronics, you can use a paper calendar or pill diary. Keep the calendar in a location that you see daily and mark down when you take your pills.
- You may also buy a pillbox labeled Sunday-Saturday at any pharmacy or medical supply store.

TROUBLE SWALLOWING YOUR MEDICATION:

If you have trouble swallowing your medication tablet or capsule you should talk to your provider. A liquid form of the drug may be available. Do not crush, split, or chew your pills as this could cause serious side effects and can have a negative impact on how well the medication works.

MEDICATION EXPENSE:

Oral cancer drugs can be very expensive and may not be fully covered by insurance. This financial burden can weigh heavily on people. It can also prevent some from following their treatment plan. If you are having trouble paying for your medication there may be help. Many drug manufacturers have plans to help people pay for their medications. Talk with your health care team. They may know about other resources to help pay for your oral cancer drugs.



SAFETY AND DISPOSAL OF ORAL CHEMOTHERAPY:

Remember oral cancer drugs are powerful and potentially hazardous. Make sure you and your caregiver take these special precautions to stay safe when handling oral cancer medications:

- Caregivers should wear disposable gloves when handling oral cancer drugs. Used gloves should never be reused. They should be double bagged and thrown in the regular household trash after one use.
- Cancer drugs should remain in their original packaging until used or placed into daily pill boxes.
- Do not let the medication come in contact with household surfaces like countertops or tables, and if they do, clean the surface thoroughly afterwards to prevent others from coming in contact with traces of the drugs.
- Whenever possible, you should handle your drugs yourself.
- Wash your hands well before and after handling the pills.
- If anyone else is giving you your medication, they should put the pill into a medication cup or onto a spoon. Then you can tip the cup or spoon to your mouth to take the pills.
- Oral cancer drugs should not be crushed, split, broken, or chewed.
- Caregivers should wash their hands with soap and water after removing and throwing away the gloves.
- Pregnant caregivers should not handle oral cancer drugs.
- Pill containers for cancer drugs should never be reused.
- **Remember to keep all drugs out of the reach of children and pets.**

STORAGE:

Keep oral cancer drugs in their original container (unless they are moved into the daily pillbox you use for your cancer medications only). Keeping your medications in their original containers will limit contamination and ensure that you always have the information about the name of the medication, the dose, and other instructions. This is especially important if you are on multiple medications.

- Do not let your chemotherapy drugs come into contact with your other medications. They should always remain separate.
- Keep your medications in a cool, dry place away from heat, sunlight, or moisture. Bathrooms can be especially humid, so do not store your pills there.
- Store oral chemotherapy drugs away from food and drinks.

DISPOSAL OF LEFTOVER MEDICATION:

You will usually not have any extra medication left over. However, if you have leftover drugs it is important to dispose of them as safely as possible. **Never throw cancer drugs in the trash or down the drain and do not flush them down the toilet.**

INSTEAD, YOU CAN:

- Ask your health care team if unused medication can be returned to the doctor's office, pharmacy, or treatment center for safe disposal.
- Check with your local health department to find out where you can safely dispose of any unused cancer drugs.
- Find an authorized collection location near you by using a locating tool on the Drug Enforcement Agency's website.
- Check with the company that collects your trash for their policy on cancer medication disposal.
- If you have additional questions about disposing unused or expired medications, ask your health care team or pharmacist. You can also call the Food and Drug Administration at 1-866-300-4374.
- Empty pill bottles may be put in the household trash. Do not recycle them. Before throwing them out, remove the label or completely cross out any personal information. Never reuse cancer medication pill bottles. Check with your local waste management organization for how to best dispose of them.

SUPPORT SERVICES

At Sylvester, we are committed to providing you and your loved ones with comprehensive, multidisciplinary care. The Cancer Support Services Department addresses the psychosocial, spiritual, nutritional, and physical aspects of wellness to enhance the medical care you receive. The support services team is located at our downtown Miami campus and at our satellite sites.

THE FOLLOWING COMPLIMENTARY SERVICES ARE AVAILABLE TO YOU AT SELECTED LOCATIONS:

- **Arts in Medicine:** The arts in medicine program can help reduce feelings of anxiety, boost morale, and support wellness through creative expression.
- **Exercise Physiology:** The exercise physiology program provides patients with an opportunity to develop practical ways of adopting a healthier, active lifestyle both during and after treatment.
- **Massage Therapy:** Our licensed oncology massage therapists round in the CTU and inpatient units to offer massages to patients during treatment. Scientific literature indicates that oncology massage can help relieve anxiety, fatigue, nausea, induce relaxation, improve sleep, as well as increase energy and appetite.
- **Oncology Social Work:** Social work can provide crisis intervention, counseling, and support. Social workers also help with referrals to community-based resources, transportation assistance, home health referrals, financial programs, and facilitate support groups.
- **Music Therapy:** Music therapy uses live music-making and music-based activities to increase feelings of wellness in patients of all ages.
- **Nutrition Counseling:** Sylvester's licensed registered dietitians are specialized in oncology and are an integral part of the medical team. Medical nutrition therapy can help with managing a variety of conditions including digestion problems, changes in taste, weight loss, or weight gain. Recommendations are based on the latest research and are personalized to the type of cancer and treatment.
- **Pastoral Care:** Our chaplains are non-denominational and provide spiritual support to patients and their loved ones. In addition, our chaplaincy program will facilitate referrals for community clergy when requested.
- **Pet Therapy:** Studies have shown that pet therapy programs can improve mood and help decrease anxiety. Our pet therapy dogs adhere to strict guidelines and are observed prior to joining our program to make sure they are a good fit with our patients.

UHealth - University of Miami Health System recognizes its responsibility to comply with the requirements of the Americans with Disabilities Act (ADA), as amended, Section 1557 of the Patient Protection and Affordable Health Care Act, as well as related federal regulations. In doing so, UHealth acknowledges the need to address instances where patients and visitors require the use of a Service Animal. Service Animals are allowed to accompany patients and visitors at UHealth's facilities as long as their presence does not pose a threat or danger to standard medical practices and does not impede fundamental services or functions. As such, a Service Animal is defined as a dog or miniature horse that has been individually trained to do work or perform tasks for a person with a corresponding disability. A dog or miniature horse that does not meet this definition, such as emotional support, therapy, comfort or companion animals are not considered Service Animals and are excluded from the ADA and federal regulations. For consideration of our patients, visitors, and employees, pets are prohibited from accompanying patients, visitors, and employees at all UHealth facilities.

- **Wigs:** In collaboration with EBeauty™, we offer wigs to our patients undergoing treatment at Sylvester. In order to receive a wig, you must have a note or prescription from your physician or APP.
- **Caregiver Support:** Providing care to someone with cancer is a difficult job and can take a toll emotionally, physically, and psychologically. At Sylvester, we provide tools and resources to help ease this burden and prevent caregiver burnout.
- **Survivorship Program:** At Sylvester, we are here to support you and your caregiver(s) through diagnosis, treatment, and after the completion of treatment. The end of cancer treatment can be a relief for patients and their caregivers, but it also can be a time of uncertainty. Sylvester has developed survivorship programs for you that includes support groups, seminars, workshops, and more. Through our research efforts, we are also looking to address the social, economic, and physical effects cancer has among our pediatric and adult patients.

THE FOLLOWING SERVICES MAY REQUIRE PRIOR INSURANCE AUTHORIZATION, WHICH IS EASILY OBTAINABLE:

- **Acupuncture:** Our team of oncology-trained acupuncturists can help to manage symptoms of neuropathy, hot flashes, poor appetite, anxiety, fatigue, and pain.
- **Psychosocial Oncology:** Our team of oncology-trained psychologists and psychiatrists provide psychotherapy for cancer-related issues and medication for mental health diagnoses.
- **Palliative Care:** The palliative care specialist helps in improving quality of life for anyone living with a serious illness, including cancer. They focus on providing you with relief from the symptoms, pain, and stresses of a health condition – whatever your diagnosis or prognosis. The team will work together with your other providers to improve your well-being, as you go through treatment.
- **Physical Medicine and Rehabilitation:** This team helps you recover to your fullest ability after your diagnosis. They look at reducing pain and restoring loss of mobility and function caused by your cancer diagnosis. The focus is your physical and emotional wellness.

If you are interested in these services or for more information, please contact Cancer Support Services at 305-243-4129.

MY CARE TEAM

MY DOCTOR (HEMATOLOGIST OR ONCOLOGIST):

The primary hematologist or oncologist is the physician that is overseeing your care. They have special training in the treatment of cancer. They will be the physician that orders the chemotherapy, biotherapy, or targeted treatment you will receive in the comprehensive treatment unit (CTU). This physician is from Sylvester Comprehensive Cancer Center.

Name: _____

Phone: _____

MY APRN OR PA:

The advanced practice provider is either an advanced practice registered nurse or physician assistant. They work with your primary hematologist or oncologist. The advanced practice provider will assess your condition, review your plan of care, and collaborate with your primary physician. These individuals have typically completed a master's or doctoral training.

Name: _____

Phone: _____

PHYSICIAN'S ADMINISTRATIVE ASSISTANT:

The physician's administrative assistant will assist you with answering questions about scheduled appointments, including rescheduling, confirming, and cancelling once you leave the clinic.

Name: _____

Phone: _____

NURSE NAVIGATOR:

The nurse navigator is a nurse with oncology-specific knowledge who coordinates your first appointment and can offer assistance to patients, families, and caregivers to overcome health system barriers.

Name: _____

Phone: _____

TRIAGE NURSE:

The triage nurse is a nurse that has been specially trained to care for hematology/oncology patients. The triage nurse will listen to any medical questions/concerns you have and will provide you with specific instructions and/or discuss the situation with your advanced practice provider or primary hematologist/oncologist if needed to address your medical questions/concerns.

Name: _____

Phone: _____

SOCIAL WORKER:

The clinical social worker provides supportive counseling, discharge planning, referrals to community resources, and assistance with financial concerns. You can request a consult to see the social worker at any time. You can contact a social worker by calling Cancer Support Services at 305-243-4129.

Name: _____

Phone: _____

FINANCIAL CASE MANAGER:

The financial case manager advocates for you by contacting your insurance company to verify treatments. Coverage may vary depending on the individual insurance company policy, Medicare, or Medicaid. The financial case manager will help you get information regarding your individual financial insurance components (i.e. co-pays, deductibles, co-insurance, out of pocket expenses, etc.).

Name: _____

Phone: _____

REGISTERED DIETITIAN:

The clinical dietitian provides evidence based nutrition information to help you through your journey. They can assist with dietary management of symptoms, as well as sound, nutrition advice for "living beyond cancer." You can request a consult to see the dietitian at any time. You can contact a dietitian by calling Cancer Support Services at 305-243-4129.

Name: _____

Phone: _____

ONCOLOGY CARE CLINIC

UHEALTH TOWER FIRST FLOOR, SUITE 1645 (ADJACENT TO EMERGENCY ROOM)

The goal of the Oncology CARE Clinic is to provide immediate care for existing Sylvester hematology/oncology patients. If you need to be seen, an advanced practice provider will evaluate you. Conditions that can be treated include chemotherapy associated side effects as well as other minor, non-emergent illnesses. Walk-ins welcome, as well as referrals from health care providers or the nurse triage line.

INSPIRING WORDS FROM A SURVIVOR

Being told you have cancer is tough enough to hear, but the follow-up phrasing almost always involves the timetable as to when you will start chemotherapy. If the terror of having cancer isn't enough, the thought of having chemo elicits even more fear and foreboding. At least it did for me! The thought of needles was the first shiver that ran down my spine because I had always hated needles (having a port put in solved that problem).

The second shiver came from the thought that they would be pouring deadly chemicals in my body to try to kill the cancer. What was that going to do to me? As most people, I had heard all kinds of horror stories about having chemo. I even had to watch my own father go through it many years before. What I didn't realize at the time was that the medical community had made great strides in controlling all the things that had made chemo so horrendous in the past. So, what I am here to tell you after having been through 11 rounds of what I always called the "nuclear bomb" of chemo, is that it really wasn't so bad. It's all about how you look at it and experience it.

My chemotherapy consisted of eight hours of infusion with three different types of chemo drugs and then a fourth chemo drug in a pack was attached and infused periodically over the next 48 hours. This was repeated every two weeks. Sounds awful, right? But, it really wasn't anywhere near as bad as what I had thought it would be. The drugs they have now to counteract nausea and other side effects are amazing and effective. I was so surprised to find that it was rather easy. Yes, there was some fatigue, but I knew I could handle that and I knew that these "poisonous" chemicals were systematically removing the cancer.

So, all you need do is take it one day at a time – knowing that each day is bringing you a day closer to being cancer-free. Expect it to be easy instead of hard. No one wants to have chemotherapy, but I am now cancer free and chemo helped get me here. Once I put the fears aside, the implementation was just a walk in the park.

- A Sylvester Survivor

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