



ROBERT H. LURIE
COMPREHENSIVE CANCER CENTER
OF NORTHWESTERN UNIVERSITY

Treatment Guide

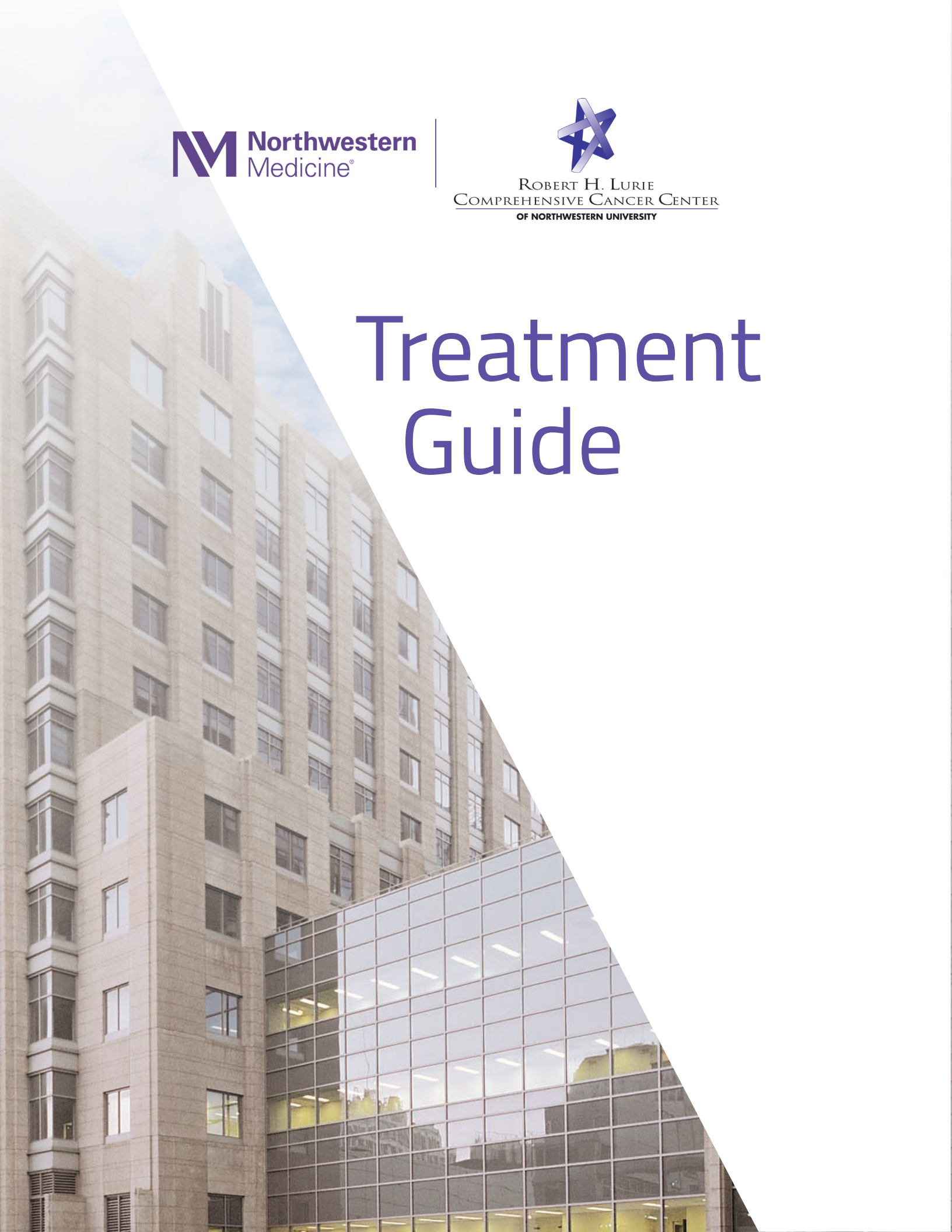


Table of Contents

Personal Notes Section 1: Page 4

- Notes

My Treatment Section 2: Page 7

- What is my Diagnosis
- Clinical Trials
- ASCO Answers
- Treatment Options

The “My Treatment” section will be filled with chemotherapy teaching sheets. You will receive these when your treatment has been determined.

Side Effects Section 3: Page 14

- Side effects and how to manage them
- Medications to manage or prevent Chemotherapy side effects
- Sexual Health
- Cognitive Changes after Chemotherapy
- Diet and Nutrition
- Managing Fatigue

Tests and Procedures Section 4: Page 37

- Computed Tomography (CT Scan)
- PORT-A- Cath

Results Section 5: Page 42

Please use this blank section to add your own results.

- Lab Results and How to Interpret Them

Schedule Section 6: Page 46

- Calendar
- After Visit Summaries (**Add your own**)

Supportive Resources

Section 7: Page 49

- Supportive Oncology Team at Northwestern
- Caring Advice for Caregivers
- Gilda's Club Chicago
- Look Good... Feel Better- American Cancer Society
- Resources in Your Community
- Supportive Care and Palliative Medicine

Personal Documents

Section 8: Page 58

- Survivorship Summary
- Voice in Your Future
- Power of Attorney Document

Section 1: Personal Notes

- Notes

Section 2: My Treatment

- What is my diagnosis?
- Clinical Trials
- ASCO Answers
- Treatment Options

What is my diagnosis?

Type of Cancer:

- Ovarian
- Fallopian Tube
- Primary Peritoneal
- Endometrial /Uterine
- Cervical
- Other _____

Grade ____ **(0-3)** Tumor grade is a system used to classify cancer cells in terms of how abnormal they look under a microscope and how quickly the tumor is likely to grow and spread

Cell Type _____

Stage _____ **(I, II, III, IV)** Staging describes the extent or severity of an individual's cancer based on the extent of the original (primary) tumor and the extent of spread in the body. Staging is important:

- Staging helps the doctor plan a person's treatment.
- The stage can be used to estimate the person's prognosis (likely outcome or course of the disease).
- Knowing the stage is important in identifying clinical trials (research studies) that may be suitable for a particular patient.

Notes:

Will I need treatment?

Observation only

- How often? _____ With whom/where? _____
- Will I need to have certain tests or labs on a regular basis? _____

Radiation Therapy _____

(Contact NMH Radiation Oncology at 312-926-2520 to set up a consultation with Dr _____ on or about _____ (Date)

Chemotherapy (see attached sheets for chemotherapy information)

Clinical Trials

What are clinical trials?

A clinical trial is a research study with human volunteers that determines the effectiveness of an investigational cancer drug. Prior to its approval, the Food and Drug Administration (FDA) requires a new drug to be tested in a clinical trial to determine its safety and effectiveness. Although today's FDA-approved cancer treatments are a result of clinical trials, not all clinical trials result in drug approvals. A non-FDA-approved drug is investigational and must undergo vigorous testing to ensure that it is safe and effective. A clinical trial is also known as a "research study", "study", or "trial".

Why are clinical trials important?

Clinical trials advance science and medicine to aid in the development of treatments that are more targeted, often with fewer side effects. Participation in clinical trials offers the potential for access to treatments that are not otherwise available. Results of clinical trials help to advance patient care, in addition to the advancement of scientific knowledge about cancer.

How can I learn about a clinical trial?

There are a few ways to learn about the clinical trials available at Northwestern:

1. By asking one of your oncology healthcare providers.
2. By website – <http://cancer.northwestern.edu/clinicaltrials/index.cfm>
3. By phone – (312) 695 - 1102
4. By email – cancertrials@northwestern.edu
5. Informed consent forms – documents that provide details about the trial, describe the risks vs. benefits, and the treatment schedule. After you decide to sign the consent form and take part in the trial, you have to right to withdraw from participation at any time.



QUESTIONS ABOUT
CLINICAL TRIALS?

312-695-1102

cancertrials@northwestern.edu

What are the clinical trial phases?

Clinical trials are comprised of different phases that provide information about the drug.

- Phase I trials test the safety of the new drug and determine how much of it should be given
- Phase II trials test the new treatment to determine if it is effective.
- Phase III trials compare the effectiveness of the new treatment against the standard drugs currently available to find out which one is better
- Phase IV trials monitor ongoing safety and side effects

When can I ask my healthcare team if a clinical trial is right for me?

Anytime you are facing a treatment decision you should ask your healthcare providers if a clinical trial may be appropriate for you. Clinical trials are not just for advanced stage cancer – clinical trials are available for all stages of cancer.

ASCO ANSWERS

OVARIAN CANCER

WHAT IS OVARIAN CANCER?

Ovarian cancer is a disease in which normal cells in an ovary change and grow uncontrollably, forming a mass called a tumor. Epithelial carcinoma, which begins in cells on the outer surface of the ovary, is the most common type of ovarian cancer. However, new evidence suggests at least some of these ovarian cancers actually begin in special cells in the fallopian tubes. Ovarian cancer is the ninth most common type of cancer diagnosed in women in the United States.

WHAT IS THE FUNCTION OF THE OVARIES?

Every woman has two ovaries, the almond-shaped glands that contain the eggs. During ovulation, an egg is released from an ovary and travels to the uterus through the fallopian tube. The ovaries are the primary source of estrogen and progesterone, the hormones that influence breast growth, body shape, and body hair and regulate the menstrual cycle and pregnancy.

WHAT DO STAGE AND GRADE MEAN?

The stage is a way of describing where the cancer is located, if or where it has spread, and whether it is affecting other parts of the body. There are four stages for ovarian cancer: stages I through IV (one through four). In addition to stage, ovarian cancer can be described by its grade, a measure of how much the tumor cells look like healthy cells. More information about ovarian cancer can be found at www.cancer.net/ovarian.

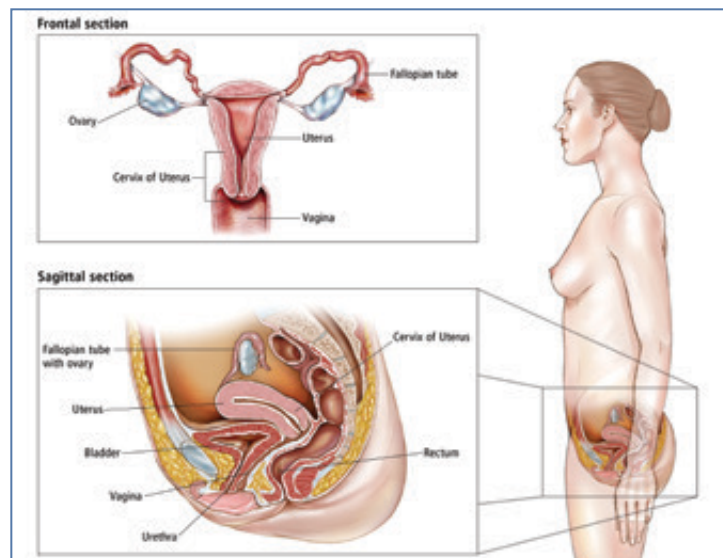
HOW IS OVARIAN CANCER TREATED?

The treatment of ovarian cancer depends on the size and location of the tumor, whether the cancer has spread, the woman's overall health, and her desire to have children. Surgery is often the first treatment and may include the removal of the ovaries, fallopian tubes, and uterus. Chemotherapy may be given depending on the goals of the treatment plan. Radiation therapy is uncommon as a first treatment for ovarian cancer, but it can be an option for treating ovarian cancer that has come back after treatment. When making treatment decisions, women may also consider a clinical trial; talk with your doctor about all treatment options.

Ovarian cancer treatment can affect a woman's sexual health and fertility (ability to become pregnant). Talk with your health care team about preventing or managing these and other side effects. This is called supportive care and is an important part of the overall treatment plan.

HOW CAN I COPE WITH OVARIAN CANCER?

Absorbing the news of a cancer diagnosis and communicating with your doctor are key parts of the coping process. Seeking support, becoming organized, and considering a second opinion are other steps. Take care of yourself during this time. Understanding your emotions and those of people close to you can be helpful in managing the diagnosis, treatment, and healing process.



Find additional cancer information at www.cancer.net.

QUESTIONS TO ASK THE DOCTOR

Regular communication is important in making informed decisions about your health care. Consider asking the following questions of your health care team:

- What type of ovarian cancer do I have?
- Can you explain my pathology report (laboratory test results) to me?
- What stage and grade is the ovarian cancer? What does this mean?
- Would you explain my treatment options? What clinical trials are open to me?
- What treatment plan do you recommend? Why?
- What is the goal of each treatment? Is it to eliminate the cancer, help me feel better, or both?
- Who will be part of my treatment team, and what does each member do?
- How will this treatment affect my daily life? Will I be able to work, exercise, and perform my usual activities?
- Could this treatment affect my sex life? If so, how and for how long?
- Will this treatment affect my ability to become pregnant?
- What long-term side effects may be associated with my cancer treatment?
- If I'm worried about managing the costs related to my cancer care, who can help me with this concern?
- Where can I find emotional support for me and my family?
- Whom should I call for questions or problems?

Additional questions to ask the doctor can be found at www.cancer.net/ovarian.



Doctor-Approved Patient Information from ASCO[®]

For more information, visit ASCO's patient website, www.cancer.net, or call 888-651-3038.

The ideas and opinions expressed here do not necessarily reflect the opinions of the American Society of Clinical Oncology (ASCO) or The Conquer Cancer Foundation. The information in this fact sheet is not intended as medical or legal advice, or as a substitute for consultation with a physician or other licensed health care provider. Patients with health care-related questions should call or see their physician or other health care provider promptly and should not disregard professional medical advice, or delay seeking it, because of information encountered here. The mention of any product, service, or treatment in this fact sheet should not be construed as an ASCO endorsement. ASCO is not responsible for any injury or damage to persons or property arising out of or related to any use of ASCO's patient education materials, or to any errors or omissions.

To order more printed copies, please call 888-273-3508 or visit www.cancer.net/estore.

TERMS TO KNOW

Benign:

A tumor that is not cancerous

Bilateral salpingo-oophorectomy:

Removal of both ovaries and fallopian tubes

Biopsy:

Removal of a tissue sample that is then examined under a microscope to check for cancer cells

CA-125:

A substance, called a tumor marker, that may be at higher levels in women with ovarian cancer and is measured with a blood test

Chemotherapy:

The use of drugs to destroy cancer cells

Gynecologic oncologist:

A doctor who specializes in treating women with cancer of the reproductive system

Hysterectomy:

Removal of the uterus

Lymph node:

A tiny, bean-shaped organ that fights infection

Malignant:

A tumor that is cancerous

Metastasis:

The spread of cancer from where the cancer began to another part of the body

Prognosis:

Chance of recovery

Radiation therapy:

The use of high-energy x-rays to destroy cancer cells

Tumor:

An abnormal growth of body tissue

First-Line Chemotherapy Treatment Plans for Ovarian, Fallopian Tube or Primary Peritoneal Cancers

| Cancer Type | Stage I | Stage II | Stage III | Stage IV |
|---|---|--|--|--|
| Ovary | Tumor confined to one/both ovaries | Spread to the uterus or pelvic tissues | Spread outside the pelvis (including lymph nodes/liver surface/upper abdomen) | Distant metastases (including cancer fluid in the lung or lung metastases). Also cancer inside the liver. |
| Fallopian Tube | Tumor confined to one or both fallopian tubes | Spread to the uterus or pelvic tissues | Spread outside the pelvis (including lymph nodes/liver surface/upper abdomen) | Distant metastases (including cancer fluid in the lung or lung metastases). Also cancer inside the liver. |
| Primary Peritoneal (cancer starting in the lining of the abdominal wall) | Not applicable | Not applicable | All primary peritoneal cancers spread in the abdominal cavity. All are considered Stage III | Distant metastases (including cancer fluid in the lung or lung metastases). Also cancer inside the liver. |

Most patients Stage I, and ALL Stage II-IV patients require post-operative chemotherapy (chemo).

In some patients, chemotherapy is given prior to having surgery. There are two main types of chemo agents that are traditionally used:

- **Taxane** : Taxol (paclitaxel) or Taxotere (docetaxel)
- **Platinum**: carboplatin (paraplatin) or Cisplatin (CDDP)

They can be given intravenously (IV) [in a vein] or intraperitoneally (IP) [in the peritoneal cavity of the abdomen via port /catheter].

Chemo is given in our outpatient infusion center (suite 420) in the Prentice building.

Treatment Plans, pg 2

The following are *treatment plans* that are most commonly administered for first line chemo in these cancers. Together we will choose the appropriate plan based on your stage and overall health. The frequency of visits and number of cycles may be different than listed below.

1 cycle = 21 days (6 cycles = 4.5months)

The cycle starts on day 1

___ Original: IV Carboplatin / IV Taxol given over 4-5 hours on day 1 for 6 cycles

___ Dose dense: IV carboplatin Day 1 / IV Taxol Day 1, 8, 15 (once weekly) for 6 cycles

___ Intraperitoneal (IP): IV Taxol or Taxotere & IP Cisplatin Day 1 / IP Taxol Day 8 for 6 cycles

- Usually IV hydration and lab draw is required on day 3 or 4 and day 11 or 12 via home health RN or in the clinic.

___ Clinical trial (your provider will discuss any options available to you)

Blood Tests are drawn prior to each treatment day (usually CBC, complete metabolic panel and sometimes Magnesium) in the lab on the 4th floor. Included in your blood draw for the first day of each cycle will be a CA125 tumor marker. The CA125 will usually be read in 2-4 hours and is *sometimes* a way in which your provider can monitor your cancer's response to chemo.

You will also have a physical exam with either your doctor or nurse practitioner prior to treatment that day. Plan to be in the office early in the morning (8-9AM) on for first day of your treatments (Day 1 of each cycle) because you will have labs, then an office visit, then chemotherapy. The nurses will confirm arrival times with you. Plan to be here approximately 6-7 hours on the Day 1 of each cycle.

Office Visits: You will see your doctor or of one of the nurse practitioners in the office (Suite 420) prior to day 1 of each treatment. At that visit you will have a physical exam and you will be asked how you tolerated the chemo. We will discuss any questions you have about the treatment, your symptoms, or any other concerns you might have.

Medications: You will be given "pre medications" and "post-medications" with your chemotherapy. The pre meds are taken at home before you come in for chemotherapy to help prevent allergic responses to the treatment. The post meds are to help control nausea after your treatment. Each chemotherapy regimen varies in their pre and post medications. We will review these medications in detail before you start chemotherapy.

Nourishment: please eat a light breakfast prior to coming. You may eat while you are receiving treatment. We have a few refreshments and snacks available, but you may want to bring a lunch or have your companion go to the cafeteria on the 2nd floor. We have a refrigerator on site where you can store your food.

Section 3: Side Effects

- Side effects and how to manage them
- Medications to manage or prevent Chemotherapy side effects
- Sexual Health
- Cognitive Changes after Chemotherapy
- Diet and Nutrition
- Managing Fatigue

SIDE EFFECTS AND HOW TO MANAGE THEM

Chemotherapy works by killing cells that divide rapidly. Cancer cells grow rapidly but so do many normal cells in your body, like the cells in your bone marrow, cells that line your mouth, stomach and intestines and cells that make your hair grow. That is why you may experience some side effects to chemotherapy. Not everyone has side effects and if you do not have any, it does not mean that the chemotherapy is not working. This section will talk about some of the common side effects and what you can do to help control them.

Infection

White blood cells help your body to fight infection. They are some of the fastest dividing cells in your body and are often affected by chemotherapy. There are different types of white blood cells. One kind that your doctor and nurse will follow closely is called a neutrophil, because these are especially important to fight infection. When this type of cell is low (often around 10 -14 days after treatment), it is very important to watch for any signs of infection. Some signs of infection are:

- Fever of 100.5 or higher
- Chills, shaking or dizziness
- Coughing up yellow or green mucous
- Sores in your mouth
- Burning when you urinate
- Diarrhea
- Difficult breathing or feeling short of breath.

What you can do to manage or prevent infection

- Good hand washing with soap and water is your best defense against infection. It is especially important to wash your hands before preparing food or eating; after you cough, sneeze, or blow your nose; after you use the bathroom or touch animals. If you have pets ask someone else to change the litter or be the “pooper –scooper”. Carry some hand sanitizer with you to use if you are not able to use soap and water.
- Clean surfaces that you touch like telephones, computers, doorknobs with disinfecting wipes.
- Try to stay away from people who are sick.
- Take good care of your mouth. Brush your teeth at least twice a day using a soft toothbrush and rinse your mouth with an alcohol free mouth wash or a salt and baking soda rinse (½ teaspoon of salt and ½ teaspoon of baking soda in 2 cups of water).
- Eat a well balanced diet. Wash raw fruits and vegetables well before eating. Do not eat raw seafood (sushi) or undercooked meat or chicken as these may contain bacteria.

Call your doctor or health care provider right away if you have a fever of 100.5 F or higher or think you have an infection. The number to call 24 hours a day/ 7 days a week is:

312-695-0990

Fatigue

Fatigue means feeling tired or weak and it is not always relieved by rest or sleep. It may last for a few days between treatments or be constant throughout treatment and last for a few weeks or months after your treatment is complete. If you are receiving radiation treatment along with chemotherapy, you may feel even more tired.

Fatigue can be a side effect of the chemotherapy drugs but some other causes of fatigue include:

- Anemia (low red blood cells). Red blood cells carry oxygen throughout your body. Chemotherapy can cause you to have fewer red blood cells and make it harder for your body to get the oxygen it needs.
- Some of the medicines we use to treat nausea, anxiety, or pain can also cause fatigue.
- Stress or depression can increase fatigue. Having cancer and receiving chemotherapy is stressful. It can affect your family life, work and finances. **We have support available to help you handle the increased stress in your life. Please talk to your doctor or nurse about your feelings, so we can get you the help you need.**

What you can do to manage fatigue

- Try to get 8 hours of sleep each night. Listen to your body. You may need a short nap or to sit down and put up your feet for a bit during the day. (Do not sleep more than an hour during the day so that you can still sleep at night).
- Getting some exercise each day such as walking or riding a stationary bike may help reduce fatigue.
- Try to balance periods of rest and activity. Let family and friends help you with some of your chores or errands.
- Eat a well balanced diet and drink 8 to 10 glasses of fluids each day. **(We have dietitians who can help you with planning to meet your dietary needs. Ask your nurse to arrange a visit).**
- Attending support groups or talking with a therapist can help you control the stress you experience.

Bleeding or Clotting

Platelets are cells that cause your blood to clot. Chemotherapy can lower the number of platelets that you have which can increase your risk for bleeding. Some types of chemotherapy work by targeting the blood vessels a tumor needs to grow. These medicines can also increase your risk for bleeding or forming a blood clot.

What you can do to manage bleeding or clotting

- Use a soft toothbrush to clean your teeth.
- Use an electric shaver instead of a razor.
- Be careful when using sharp objects.
- Blow your nose gently. It may help to use nasal saline spray to keep your nose moist.
- Wear shoes, even indoors, to protect your feet.
- Do not play contact sports or other activities that could injure you.
- Drink plenty of fluids and increase fiber in your diet to prevent straining to have a bowel movement.

- Try not to cross your legs when sitting as this can affect your blood circulation.
- Do not take aspirin or over the counter medicines, vitamins or herbal supplements unless you check with your doctor or nurse.

Call our office at 312-695-0990 if:

- You have bleeding from your nose or a cut that you cannot stop with firm pressure.
- You have red or pink colored urine.
- You have blood in your bowel movements or they look black and tarry.
- You have heavy vaginal bleeding during your period or bleeding when you are not having a period.
- Swelling, warmth, or tenderness in your leg or arm.
- You have headaches or changes in your vision.

Nausea and Vomiting

Some chemotherapy can cause you to feel sick to your stomach (nausea) or like you are going to throw up (vomiting). Usually the risk of this is greatest in the first 24 to 48 hours after you are treated. There are many good drugs to control nausea and vomiting. If you are receiving a treatment which can cause nausea, your nurse will give you some medicine before the chemotherapy to help prevent it. You will also be given prescriptions for medicine to take at home with instructions on when and how to use it.

What you can do to manage nausea and vomiting:

- Take your medications exactly the way your nurse instructs you, even if you do not think you need it. It is easier to prevent nausea than get rid of it after it happens. **If your medicine does not seem to work, please call your nurse or doctor. There are many different kinds of anti nausea medicine and if one doesn't work we can prescribe another.**
- Eat simple, bland (non-spicy) foods on the day you are treated like soup, eggs, toast or plain pasta. You may also find it easier to eat small, frequent meals instead of 3 large ones.
- Foods that are not too hot or too cold may be better tolerated.
- Try to stay away from foods with strong smells.
- Drink 8-10 glasses of clear, caffeine free fluid daily.
- Acupuncture may also help with nausea. There is an acupuncture therapist available on certain days and times in the clinic, or an appointment can be made at the *Center for Integrative Medicine*. Your nurse can give you the information.

Call our office at 312-695-0990 if:

- You are experiencing nausea and vomiting at home despite taking your anti nausea medicine
- You feel weak or dizzy.
- You are not making as much urine as you usually do or it is dark in color.

Hair Loss

Some chemotherapy drugs damage the cells that cause your hair to grow. You may lose all of your hair or just have some thinning of your hair. Hair loss can affect all of your body hair – face, eyebrows, eyelashes, arms, legs, underarms, and pubic hair. If you are receiving a drug that causes hair loss, it usually starts about 2 to 3 weeks after your first treatment. It may gradually thin or fall out in clumps. Many people find it easier to cut their hair short or shave their heads when this happens. Your scalp may feel tender or tingly when hair loss is about to begin. Your hair usually begins to grow back about 2 months after completing treatment but it may be different in color or texture.

What you can do to manage hair loss

- Ask your doctor or nurse if you are likely to have hair loss.
- Be gentle with your hair. Use baby shampoo and pat it dry. Avoid use of hair dryers, curling irons, hair dyes, or perms as these can damage your hair.

If you are interested in obtaining a wig, it is best to do this before you start chemotherapy so that you can match your color and style. Some insurance companies will pay for a wig with a prescription from your doctor. The American Cancer Society can also provide a wig for you.

- Some people are more comfortable covering their heads with a scarf or hat.

Diarrhea

Diarrhea means that you have bowel movements more often than normal, and they may be watery or very soft. If you have an ostomy, diarrhea means that your bag is filling up faster and your stool may be softer or more watery. Some types of chemotherapy can cause diarrhea. Radiation therapy to your abdomen or pelvis can also cause diarrhea.

What you can do to manage diarrhea:

- Imodium (loperamide) is an over the counter medicine used to control diarrhea. Use it the way your nurse or doctor tells you (this may be more often than the package directs). **If it does not work be sure to let your nurse know as there are other medications that can be used.**
- Drink 8 to 12 glasses of fluids every day to stay well hydrated. Water, clear soda like ginger ale, apple juice, clear chicken broth or Pedialyte are good choices. Alcohol and caffeine can make diarrhea worse.
- Eat small frequent meals instead of 3 large ones. Avoid greasy or spicy foods, or foods that cause gas like cabbage or broccoli.
- Soft, bland foods like bananas, white rice, applesauce, toast, eggs, plain noodles, jello, or baked chicken or turkey without the skin are good choices.
- Clean your skin gently after a bowel movement. Use a baby wipe or squirt bottle with warm water to clean yourself. You may need to use an ointment like Desitin or A&D to soothe your skin.

Call our office at 312-695-0990 if:

- You have a fever of 100.5 degrees F or higher.
- You feel weak, dizzy, or short of breath.
- The medicines you are taking for diarrhea are not helping.
- You notice blood in your stools or dark, tarry stools.

Constipation

Constipation means that it is hard to have a bowel movement. Your stools may be harder than normal and you may have more gas and bloating. Some chemotherapy can cause constipation. Pain medicines or some of the medicines to prevent nausea can cause this too.

What you can do to manage constipation:

- Drink plenty of liquids. Try to drink at least 8-10 glasses every day. Prune juice or other fruit/ vegetable juices may help.
- Eat high fiber foods like bran, whole wheat bread, fruits, vegetables, nuts, or popcorn

- Stay active! Walking or riding an exercise bike can help.
- Your doctor or nurse may recommend a laxative like Senna –S or Miralax. **Do not use an enema or suppository without asking your nurse or doctor first.**

Call our office at 312-695-0990 if:

- You have not had a bowel movement for 3 days.

Mouth Sores

Some types of chemotherapy can cause your mouth to feel dry or cause sores in your mouth, throat or around your lips (like canker sores). This can make it harder for you to eat and drink.

What you can do to manage mouth sores:

- If possible, see a dentist before starting chemotherapy to have your teeth cleaned and take care of any problems you may have. If you must go to the dentist while on chemotherapy, let your doctor or nurse know so they can check your blood counts and make sure it is safe.
- Keep your mouth clean. Brush your teeth after eating and at bedtime using a soft tooth brush.
- Rinse your mouth frequently (4 or 5 times a day) with a salt and soda solution (½ teaspoon salt and ½ teaspoon baking soda in 2 cups water). Or you may use Biotene available over the counter. Do not use mouth wash that has alcohol in it as this can dry your mouth more.
- If your mouth is sore eat foods that are soft and moist like scrambled eggs, mashed potatoes with gravy, or pudding. Stay away from citrus (oranges, lemon or grapefruit), crunchy foods or foods that are spicy.
- Tobacco and alcohol can also aggravate mouth sores.
- If your mouth is dry, suck on hard candy or chew sugarless gum.
- Sucking on ice chips or popsicles may also help dry mouth and to relieve pain if mouth is sore.
- Keep your lips moist with a moisturizer like petroleum jelly (Vaseline) or lip balm.

Call our office at 312-695-0990 if:

- You have sores in your mouth that are making it hard to eat or drink. You may need pain medication or a special mouth rinse to help.
- If you have a fever of 100.5 degrees or higher.

Neuropathy

Some types of cancer treatments can damage nerves. This is called neuropathy. There are different types of nerve related symptoms that you could have. They usually get better after treatment is finished but it can take many months and some may not go away completely.

- Numbness, tingling or burning especially of your hands and feet.
- Pain when you walk.
- Jaw pain.
- Shaking or trembling
- Constipation
- Trouble buttoning clothing or picking things up.
- Hearing loss
- Sometimes you may feel like it is harder to talk or feel strange sensations in your mouth or tongue during or shortly after treatment. This usually goes away quickly.

What you can do to manage neuropathy:

- **Talk to your doctor or nurse about any symptoms you have. It may be necessary to change the doses on some of your drugs or medicines may be prescribed to help.**
- Be safe! Wear rubber sole (non-skid) shoes inside and outside. Place a bath mat in your tub or shower. Remove any area rugs or cords that you could trip on. Make sure your bath/ shower water is not too hot.
- Use hot pads to protect your hands in the kitchen when cooking, and be very careful when using knives or scissors.
- Wear gloves when working outside or washing dishes. Use gloves or pads to protect your hands when getting something from the refrigerator or freezer. Let cold foods come to room temperature before eating.

Skin and Nail Changes

Chemotherapy can cause changes in your skin and fingernails. Your skin may feel dry and itchy or you may notice tenderness and peeling especially of the palms of the hands and soles of the feet or have a rash. Some drugs can cause a rash that looks like acne on your face, neck, back and chest. Your nails may be brittle and crack or you may get tender areas around your nail beds. You may also get a sunburn more quickly when on chemotherapy. Some drugs may cause darkening along your veins where the IV medicine was given.

What you can do to manage skin changes:

- If you are getting a drug that is likely to cause a rash, your doctor may have you see one of our dermatologists (skin doctor) who will give you medicines and creams to help.
- To help with dry skin, take quick showers instead of long baths; use a mild moisturizing soap; pat dry gently and use lotion or creams while skin is still damp.
- A dusting of cornstarch may help itching or using a colloidal oatmeal bath (you can buy over the counter) may also help.
- Avoid direct sunlight; wear a hat when outdoors and use a sunscreen with an SPF of at least 15 (30 is better!)

Medications to manage or prevent chemotherapy side effects

Prescribe

This is a function that allows us to submit your prescription electronically to your preferred pharmacy so it ready when you arrive. Please remember to give us your pharmacy information.

Common Side Effects:

There are several side effects and symptoms related to cancer and chemotherapy we can help to alleviate with over the counter (**OTC**) and prescription (**Rx**) medications. We have listed many options below; your provider will help suggest which medications are best for you.

Allergic reactions

Nausea

Constipation

Muscle/Joint aches

Mouth Sores

Peripheral Neuropathy *

Skin reactions *

Hot Flashes *

Fatigue *

Depression/Anxiety *

*Talk to your provider about management

Preventing Allergic Reactions

Decadron (Dexamethasone):

This is a steroid medication used as a pre-medication prior to Taxane based chemotherapy drugs to help prevent allergic reactions. It is also used after chemotherapy to help control nausea.

Decadron can increase your blood sugar. If you have diabetes, we may adjust your dose.

Decadron 4mg tablets Rx

For Taxol:

Take _____ tablets the night before (6 pm - 10pm) with food.

For Taxotere:

Take _____ tablets twice a day starting the day prior to chemotherapy and continue for _____ days. (8am and 8pm)

Benadryl/Allegra/Claritin OTC

Anti-allergy medication. Take only if recommended by your health care provider.

Anti-nausea Medication

We will suggest which medications are appropriate based on your chemotherapy regimen. All of the following are available by prescription only (Rx).

ACUTE nausea +/- vomiting = a few minutes to hours after chemo until 24 hours

DELAYED nausea +/- vomiting = >24 hours, peaks 48-72 hours and can last up to 7 days

___ **Decadron (dexamethasone)** 4mg tablets before and/or after chemotherapy to prevent ACUTE and early DELAYED nausea after chemo:

Take ___ tablet(s) twice a day starting the morning after chemotherapy and continue for ___ days.

___ **Ativan (lorazepam)** 0.5mg, 1-2 tablets every 6 hours as needed for nausea ANYTIME.

**Can make you sleepy

___ **Compazine (prochlorperazine)** 10mg tablets every 6 hours or 25mg rectal suppository every 12 hours as needed for nausea ANYTIME. **Can make you sleepy. Do not combine with Reglan.

___ **Zofran (ondansetron)** 8mg ODT's (dissolves under the tongue) every 8 hours as needed for nausea ACUTE or DELAYED. Others in this drug class are Anzemet or Kytril.

** Can cause headache and constipation. Take stool softeners and laxatives as needed.

** May be taken at the same time as any of the other meds listed here.

___ **Reglan (metoclopramide)** 20mg every 4-6 hours as needed for nausea ANYTIME.

**Best taken 30 minutes prior to meals

** Do not combine with Compazine.

___ **Emend (aprepitant)** 125mg before chemotherapy/or may be given IV in the office for ACUTE or DELAYED nausea. This is followed by 80mg day 2 and day 3 after chemotherapy.

___ **Aloxi (palonosetron)** 0.25mg IV (long-acting form of Zofran) to be given before chemotherapy for ACUTE or DELAYED nausea.

**Can cause headache and constipation

** We often use this when patients have nausea despite the use of Zofran.

___ **Scopolamine Patch 1.5mg.** Change patch every 3 days. Good for nausea related to dizziness

** Can cause dry mouth and blurry vision

___ **Haloperidol** 1-2mg oral every 4-6 hours as needed

Non-pharmacological interventions likely to be effective:

- Acupuncture
- Accupressure
- Guided imagery
- Music therapy
- Progressive muscle relaxation
- Psychoeducational support

Prevention of constipation related to chemotherapy

Many people notice increased constipation the week after receiving Taxol chemotherapy. If not effective, see the "constipation action plan" below.

___ **Colace (docusate sodium) 100mg OTC.** Take 1 tab twice daily starting 2-3 days prior to chemotherapy (stool softener).

___ **Senokot (Senna)OTC** take 1 -2 tabs the night after your chemotherapy, then once daily for 3 days, then as needed.

Constipation Action Plan

Non medication things to try:

- Drink 2-3 liters of fluid per day (especially if you take fiber supplement or have a high-fiber diet)
- Try to get moderate exercise 20-30 minutes per day
- Limit alcohol to 1 glass per night
- Try ground fresh flax seeds over your cereal. Also tastes great toasted then ground with a little salt
- Try fresh celery sticks
- Try prune juice or pureed prune baby food (still a great option after all these years)

Step 1:

___ **Metamucil, Citrucel, Benfiber (fiber supplement) OTC.** Take as directed (1-2 tsp. 1-3x/day) with a full glass of water. This will not help you if you are not able to drink enough fluids or if you regularly take opioid medications.

___ **Colace (docusate sodium) 100mg OTC.** Take 1-4 tabs daily. (stool softener).

If no BM in 24 hours then increase doses listed above

Step 2: If no BM in 48 hours then continue Step 1 and add:

___ **Dulcolax (bisacodyl) pills 5mg (Rx)** 2-3 tabs before bed or up to 3x/day

Or

___ **Miralax 17g (OTC or Rx).** Mix with water or juice 1-3x a day.

Or

___ **Milk of Magnesia.** Take as directed (30 to 60ml) 1-2x/day.

Or begin an osmotic laxative:

___ **Lactulose** 30ml. Take 1-2x a day as needed for constipation.

___ **Magnesium Citrate Solution** (flavored carbonated) (OTC) 300 ml/24 hours by mouth

Step 3, below

Step 3: If no BM in 72 hours you may need to determine if you are impacted (this occurs when large amounts of hard, dry feces accumulates in the rectum and cannot be eliminated. You may even have small amounts of liquid stool seeping from around the impacted stool. You may feel rectal discomfort, lower abdominal or back pain, pain when defecating, or urine incontinence. Sometimes you may need a digital rectal exam to determine if you are impacted).

If you **are not** impacted, begin stimulant laxative:

___ **Senokot (senna)**

___ **Senna tea** (Smooth Moves by Traditional Medicinals).

___ **Senokot-S** (laxative + stool softener)

Take 2 tabs before bed day 1, if no BM then take 2 tabs the next am, if no BM then take 3 tabs before bed, if no BM then continue 3 tabs 2x/day

If you **are** impacted, begin suppository or enema:

___ **Glycerin suppository (OTC).** 1 suppository per rectum as needed or

___ **Dulcolax suppository (OTC)** 1 suppository per rectum 1-2x as needed or

___ **Fleet enema** 21.3Gm instill rectally as needed
___ try topical anesthetic to decrease pain

___please lubricate rectum with KY jelly or Astroglide or mineral oil enema

___Gently disimpact with a gloved finger, may follow with soap suds or tap water enema THEN, begin Senna protocol in column 1

A word about constipation for the gynecologic cancer patient.

We receive many phone calls to our office related to concerns for this problem and it is understandable.

- Most of our patients have had an abdominal surgery that may have involved a resection of the colon and were strongly encouraged to have soft bowel movements (BM) in the post-operative period
- Many patients take opioid pain medications which are well known to cause constipation
- Some patients may have known scar tissue or tumor implants in their abdomen or near the colon and are concerned about a risk for a bowel obstruction (see below)
- Many chemotherapies cause constipation

SIGNS/SYMPTOMS OF A BOWEL OBSTRUCTION:

- WAVES OF CRAMPY ABDOMINAL PAIN (ESPECIALLY AROUND THE UMBILICUS)
- VOMITING
- NO BOWEL MOVEMENTS AND INABILITY TO PASS GASS (ALTHOUGH SOMETIMES DIARRHEA AND GAS MAY BE PRESENT WITH A BOWEL OBSTRUCTION)
- ABDOMINAL BLOATING

When to call the office 312-695-0990:

- 1) If you are concerned about symptoms of a bowel obstruction call 24 hours per day
- 2) If you have not had a BM in 3 days despite trying the options listed above or have questions about management, try to call between the hours of 8-5.

Muscle / Joint aches after chemotherapy:

OTC:

___ **Tylenol (acetaminophen)** 500mg. Take 1-2 tabs every 6 hours as needed for pain.

___ **Motrin (Ibuprofen)**. Take 200mg. Take 1-2 tabs every 4-6 hours as needed for pain.

** Do not take while on blood thinners or if you have low platelets.

___ **Aleve (naprosyn)** 1 tab every 12 hours

Rx:

___ **Ultram (tramadol)** 50mg. Take 1-2 tabs every 4 hours as needed for pain.

** This will not make you sleepy. It is a mild pain medication.

___ **Norco** (acetaminophen/hydrocodone) Take 1-2 tabs every 4 hours as needed for pain.

** This medication is combined with Tylenol-do not combine additional Tylenol with it.

** Causes drowsiness and constipation. Add a stool softener +/- or laxative if you are taking this.

Prevention of low white blood cell counts:

Neupogen (filgrastim) 300mcg subcutaneous injection

This medication is given by injection daily for 3-7 days as instructed.

The nurses will teach you or a family member how to do the injections at home.

It is used to help prevent your white blood cell count from getting too low and helps to prevent fever and infections associated with low white blood cell counts.

This is used *only* when your provider is concerned about low white blood cell counts.

It is NOT used with every chemotherapy regimen.

It can cause body aches and bone pain that can be relieved with Tylenol or other prescription pain medication.

Neulasta (pegfilgrastim) 6mg subcutaneous ONE time the day of or the day after chemotherapy.

This is a LONG ACTING form of Neupogen.

It is given once after chemotherapy.

We can give it to you in the office.

You should not receive chemotherapy again for at least 14 days after this injection.

It can cause body aches and bone pain that can be relieved by Tylenol or other prescription pain medication.

Mouth Sores (Mucositis)

If you have mild soreness or mouth redness:

-brush with a soft toothbrush 4x/day and floss daily

-rinse with a bland **salt and soda rinse** (1/4 teaspoon baking soda , 1/8 teaspoon salt, 1 cup of warm water) Mix well until salt dissolves. Rinse your mouth gently, being careful not to swallow the mixture.

Follow this with a plain water rinse to clean out any remaining salt or soda.

-apply a lip moisturizer

If you have painful redness, swelling, or ulcers:

****Call the office if you have pain that prevents you from eating, drinking, or swallowing**

-increase the bland mouth rinse and oral hygiene above to every 2-4 hours

- try oral analgesics such as Tylenol, or Norco

-Use protective agents: **Gelclair Dosepack** concentrated gel (RX only, often pharmacies do not carry) to coat the mouth

-Use numbing agents: **Magic mouthwash**

The most popular formulation of magic mouthwash contains viscous lidocaine as a topical anesthetic, diphenhydramine (Benadryl elixer) as an anti-inflammatory, and *Maalox* to help coat the tissues in the mouth. Other formulations include antifungals, corticosteroids and/or antibiotics. These are not considered effective in treating mucositis, but may temporarily help the pain. These are typically compounded in a pharmacy by prescription only. We can prescribe a "recipe" for the pharmacist. Common ingredients include:

- Diphenhydramine - an antihistamine to reduce inflammation
- Glucocorticoids - to reduce inflammation
- Lidocaine - a local anesthetic to relieve pain

- Maalox - an antacid formulation which acts as a coating agent
- Nystatin- an antifungal for candidiasis
- Sucralfate - a coating agent
- Tetracycline - an antibiotic
- Erythromycin- an antibiotic

-For for crusted sores use **Peroxide Rinse**

1 cup hydrogen peroxide

1 cup water or

1 cup saltwater (1 teaspoon of salt in 4 cups of water)

If you have crusty mouth sores, try using this rinse three or four times a day for two days. Don't use it for more than two days at a time, because it will prevent mucositis from healing. Use a non-peroxide rinse for two days, before returning to this mixture.

*Sexual health
often is a concern
for patients
undergoing
cancer treatment.*

Sexual Health and Cancer

Sexual health is the state of well-being that focuses on our feelings about our own sexuality, and may include the physical, emotional and cultural aspects of sexual well-being.

What is sexuality?

Sexuality may include:

- Our bodies.
- The act of sex.
- Our sexual orientation.
- Gender identity (male or female).
- Our values about life, love and the people in our lives.

Will my sexual desire change as I go through cancer treatments?

You may notice a change in your sexual desire during cancer treatment. This may be due to:

- Pain.
- Fatigue.
- Changes in hormones.
- Depression and anxiety.
- Changes in your self-image.

How can I express intimacy without sexual intercourse?

Love and affection can be expressed in many ways.

- Kissing.
- Hugging.
- Fondling.
- Cuddling.
- Touching.
- Holding hands.

What should I do if I want to have sex with my spouse/partner?

Talk to your doctor or nurse to see if it is all right to engage in sexual acts during active cancer treatment.

Questions to ask your doctor or nurse during cancer treatment:

- When can I have sex?
- What can I expect?
- What can I do to protect myself and my partner during sex?
- Are there any restrictions on sexual activity during or after treatment?

Precautions during sexual activity:

- Use a barrier contraceptive, such as condoms. This prevents exchange of body fluids. During cancer treatment, semen and vaginal fluids may contain chemotherapy by-products. Barrier methods also help prevent the spread of STDs (sexually transmitted diseases).
- Use 2 forms of protection to prevent pregnancy. Chemotherapy may affect male semen and female eggs. Medicines you are taking may be harmful to a developing fetus. Talk to your doctor or nurse about birth control methods (e.g., condoms, spermicide, diaphragms and cervical caps).
- Before having intercourse, your neutrophil count should be over 2,000 cells/mm³. If your counts are lower than this, talk to your doctor or nurse. A low neutrophil count increases your risk for infection. When your white blood cell count is very low, the pressure of sex may cause bacteria from the vagina or rectal areas to get into the bloodstream. You may get sick if this happens. To help prevent this from occurring, it is recommended that you wash your genitals before and after sex.
- Before having intercourse, your platelet count should be above 50,000 cells/mm³. When your platelet count is low, you have a greater risk for bleeding.
- To promote hygiene during sexual acts: Wash hands before and after sexual activity. Avoid rectal intercourse, which can increase your risk of infection and risk of bleeding.
- Avoid excessive friction during intercourse by using a water-based lubricant, such as K-Y Jelly® or Astroglide®. Do not use petroleum-based jellies or lubricants.
- Report any unusual pain, fever, bleeding or discharge to your doctor or nurse.

Important signs and symptoms to report to your doctor or nurse:

- Changes in sexual drive.
- Men: Genital pain, pain during erection and/or ejaculation or problems having an erection.
- Women: Dryness in the vagina, unusual discharge from your vagina, hot flashes, pain during sex, discomfort, bleeding during or after intercourse.

Tips to promote sexual health:

- Be responsible.
- Get professional help when needed.
- Talk with your healthcare provider.
- Talk to your partner about your feelings.
- Take time for intimacy other than intercourse.
- Keep an open mind about ways to feel sexual pleasure.
- Focus on your physical recovery first. It's OK not to have sex.

Health Information Resources

For more information, visit Northwestern Memorial Hospital's Alberto Culver Health Learning Center. This state-of-the-art health library is located on the 3rd floor of the Galter Pavilion. Health information professionals are available to help you find the information you need and provide you with personalized support at no charge. You may contact the Health Learning Center by calling 312-926-LINK (5465) or by sending an e-mail to hlc@nmh.org.

Para asistencia en español, por favor llamar al Departamento de Representantes para Pacientes al 312-926-3112.

The entities that come together as Northwestern Medicine are committed to representing the communities we serve, fostering a culture of inclusion, delivering culturally competent care, providing access to treatment and programs in a nondiscriminatory manner and eliminating healthcare disparities. For questions, please call either Northwestern Memorial Hospital's Patient Representatives Department at 312-926-3112, TDD/TTY 312-944-2358 and/or the Northwestern Medical Group Patient Representatives Department at 312-926-1920, TDD/TTY 312-695-3661.

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For additional information about Northwestern Memorial Hospital, please visit our website at www.nmh.org.
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Cognitive Changes After Chemotherapy

Cancer treatments such as chemotherapy and radiation therapy can cause problems with cognitive (mental) functioning. Patients can experience changes such as trouble with concentration or memory. The effects are sometimes referred to as “chemobrain” or “chemo fog”. Health care providers are unable to predict which patients might be affected by this treatment side effect. Patients may notice this problem during chemotherapy treatment as well. Typically, patients find these difficulties greatly improve or no longer exist within one year of treatment.

Symptoms:

- Trouble remembering things (difficulty with short-term memory)
- Trouble paying attention or with concentration
- Trouble finding the right word
- Difficulty with new learning
- Difficulty multitasking
- Taking longer to do things
- Trouble setting priorities

Causes:

The exact cause of cognitive changes is unclear. The possible causes that can contribute to these difficulties include:

- Low blood counts
- Stress
- Depression or Anxiety
- Fatigue or difficulty sleeping
- Certain medications
- Hormone changes from some treatments

What You Can Do to Cope:

- **Make lists.** Carry a pad with you and write down the things you need to do. For example, keep lists of things to buy, errands to run, phone calls to return, and even the times you need to take your medicines. Cross items off as you finish them.
- **Use a portable planner or personal organizer.** These can help you stay on top of day-to-day tasks and keep track of appointments and special days like birthdays and anniversaries. Paper and electronic versions are available.
- **Organize your environment.** Keep things in familiar places so you will remember where you put them.
- **Avoid distractions.** Work, read, and do your thinking in an uncluttered, peaceful environment. This can help you stay focused for longer periods of time.
- **Keep your mind active.** Do crossword puzzles and word games, or go to a lecture on a subject that interests you.
- **Proofread.** Double-check the things you write to make sure you’ve used the right words and spelling.
- **Exercise, eat well and get plenty of rest and sleep.** Research shows that these things help keep your memory working at its best.
- **Tell your loved ones what you’re going through.** Depending on how private a person you are, you might tell your family and friends, so that they’ll understand if you forget things you normally wouldn’t forget. They may be able to help and encourage you.



Changes in Taste and Smell

Cancer and its treatment can cause changes in your senses of taste and smell. These changes can affect your appetite. Regularly rinsing and brushing can help keep your mouth clean, healthy, and tasting better. Your senses of taste and smell can change from day to day. Try experimenting with new foods or cuisines, marinades, spices, and ways of preparing what you eat.

How to Get Rid of Bitter or Metallic Tastes

- ◆ Use sugar-free lemon drops, gum, or mints.
- ◆ Flavor foods with spices and seasonings, such as onion, garlic, chili powder, basil, oregano, rosemary, tarragon, barbecue sauce, mustard, catsup, or mint.
- ◆ Use plastic utensils instead of stainless flatware.

Tasting Tips

- ◆ Season foods with tart flavors, such as lemon wedges, citrus fruits, vinegar, or pickled foods. Caution: if your mouth or throat is sore, tart foods can cause discomfort.
- ◆ If foods taste too salty, bitter, or sour, try adding sweeteners or a little bit of sugar. A little sweetness can help increase pleasant tastes.
- ◆ If red meats taste strange, try other protein-rich foods, such as poultry, fish, eggs, dairy products, beans, tofu, and soy milk. Marinating and cooking meats in sweet juices, fruits, acidic dressings, or wine can also help. For example, try sweet-and-sour pork with pineapple, chicken with honey glaze, or London broil in Italian dressing.
- ◆ Blend fresh fruits into shakes, ice cream, or yogurt. Eat frozen fruits, such as whole grapes and mandarin orange slices, or chopped cantaloupe or watermelon.
- ◆ To help clear your taste buds before eating, rinse your mouth regularly with a solution of 1 quart water, $\frac{3}{4}$ teaspoon salt and 1 teaspoon baking soda. Avoid mouth rinses that contain alcohol if your mouth is sore or irritated.
- ◆ Fresh vegetables may be more appealing than canned or frozen ones.

How to Improve Smells

- ◆ Cover beverages, such as liquid nutrition supplements, and drink from a straw or use a child's covered drinking cup.
- ◆ Choose foods that do not need to be cooked, such as cold sandwiches, crackers and cheese, yogurt and fruit, or cold cereal and milk.
- ◆ Serve foods cold or at cooler temperatures. Foods served hot often have stronger smells and flavors.
- ◆ Avoid eating in rooms that are stuffy or too warm, as well as places that have strong food or cooking odors.

High –Calorie / High – Protein Diet

Good nutrition is important for individuals being treated for cancer. Individuals with cancer often have side effects of their treatment including poor appetite and weight loss. If an individual with cancer maintains adequate nutrition, then he/she may better tolerate surgery, chemotherapy or radiation and experience fewer side effects, heal and maximize quality of life.

Here are some tips which may help you through your cancer journey. Individuals with cancer are different and unique so not every food is for everyone. Individuals with cancer often have increased calorie and protein needs. Protein is needed to help the body repair itself. Getting enough calories can help the body grow, heal or prevent weight loss.

If you have further questions or need guidance, please contact our dietitian at 312-695-2423.

Tips for increasing calories:

| High Calorie Foods | Add or mix options |
|---|--|
| Olive oil or Canola Oil (100 cal/Tbsp) | Add to casseroles, sandwiches, eggs, vegetables, breads, and pasta |
| Butter or margarine (100 cal/Tbsp) | Add to pudding, casseroles, sandwiches, eggs, vegetables, cooked cereal, breads, and pasta |
| Cheeses (100 cal/oz., 7 gm protein/oz.) | Give as snacks, or in sandwiches. Add to casseroles, potatoes, vegetables, and soups. |
| Mayonnaise or salad dressing (100 cal/Tbsp): | Use liberally on sandwiches, salads, as a dip for raw vegetables or sauce on cooked vegetables |

| | |
|--|---|
| Evaporated milk (25 cal/Tbsp, 1 gm protein/Tbsp) | Use in place of whole milk in desserts, baked goods, meat dishes, and cooked cereal |
| Sour Cream (26 cal/Tbsp) | Add to potatoes, casseroles, and dips. Use in sauces and baked goods. |
| Natural nut butter (100 cal/Tbsp, 4 gm protein/Tbsp) | Serve on toast, bagels, crackers, bananas, apples, and celery. |
| Eggs (80 cal/egg, 7 gm protein/egg) | Add to casseroles, meat loaf, mashed potatoes, macaroni and cheese, and chicken or tuna salads. |
| Carnation Instant Breakfast (130 cal/packet, 7 gm protein/packet) | Add to milkshakes or milk |
| Whey protein powder (100 calories, 20 grams protein/scoop) | Sprinkle on ice cream, cereal, cake and muffins Try making banana bread, zucchini bread and spread with butter/margarine or cream cheese. Make your favorite milkshake with protein powder and freeze it into Popsicle molds. |
| Wheat germ (25 cal/Tbsp) | Add 1 to 2 Tbsp to cereal. Mix into meat dishes, cookie batter, and casseroles |
| Nuts (if tolerated) | Sprinkle on ice cream, hot cereal or cold cereal Add to shakes, smoothies, bread, muffins Eat as a snack by itself or with dried fruit |

Tips for increasing protein:

| High Protein Foods | |
|--------------------------------------|---|
| meats | beef, chicken, fish, turkey (leaner meats preferred, such as loin or round) |
| milk and cheese | yogurt, cottage cheese, cheese, milk, soy milk, almond milk, rice milk |
| eggs | |
| Nut butters | natural peanut butter, soy butter, almond butter |
| dried beans, lentils and peas | Kidney beans, black beans, garbanzo beans, lima beans, pinto beans, black-eye peas, green peas, lentils |
| tofu or seitan | |
| soy/whey protein powder | |

High Calorie Snacks:

- Instant breakfast drink (280 cal):
 - 1 packet Carnation Instant Breakfast, 8 oz whole milk
- Instant breakfast shake (400 cal):
 - 1 packet Carnation Instant Breakfast, ½ c. whole milk or boost Plus/Ensure Plus, ¾ c. ice cream- mixed in blender
- cheese toast (175 cal/slice):
 - 1 oz. cheese, 1 slice toast
- peanut butter and jelly sandwich (555 cal):
 - 2 sl. bread, 2 Tbsp peanut butter, 1 Tbsp jelly
- bagel and cream cheese, jelly (530 cal):
 - 4 oz. bagel, 1 oz. cream cheese, 1 Tbsp jelly
- pizza (400 cal):
 - 2 slices thin crust cheese pizza
- egg and cheese on an English muffin (285 cal):
 - 1 egg, 1 oz. cheese, and 1 English muffin
- natural peanut butter and banana on toast (350 cal):
 - 2 Tbsp natural peanut butter, 1 banana, 1 slice of toast
- granola and yogurt (500 cal):
 - 1 cup granola, 1 cup yogurt
- tuna/chicken/egg salad with mayo on crackers (500 cal):
 - 1/2 cup salad, 5 crackers
- chips and guacamole (300 calories)
 - 1 oz chips and ¼ cup guacamole.

How to Manage Fatigue During Cancer Treatment

Having fatigue does not always mean that your treatment is not working or that your illness is getting worse.

Fatigue means feeling tired, exhausted, weary or not having the energy to do your daily activities. Fatigue is a common side effect of chemotherapy and/or radiation therapy.

- Many people feel very tired or exhausted during their treatment.
- Having fatigue does not mean that your treatment is not working or that your illness is getting worse.

Here are some helpful tips to lessen fatigue and increase your energy level:

Keep Moving

Exercise for 15 to 30 minutes, 3 to 5 days a week. Start out slowly and increase the pace over time.

Good exercises for fatigue are:

- Walking.
- Biking.
- Chair exercises.
- Light aerobic or water exercises.

Eat Well

Your taste will change during your treatment. Try new foods and seasonings.

Be sure to:

- Drink lots of liquids, at least 8 glasses a day.
- Eat foods high in protein and calories, such as chicken, fish, lean meats, avocados and nuts.

Time savers

- Plan your menu in advance.
- Prepare detailed shopping lists.
- Prepare your meals when you are feeling well.
- Make extra food and freeze or refrigerate.

Patients First

Increase your enjoyment

- Eat in a relaxed and pleasant place.
- Plan your day so you are not overly tired just before meals.

Rest

Plan

- Set a bedtime and a wake-up time.
- Avoid long naps or naps in the late afternoon.
- Do not eat heavy meals or drink a large amount of liquid before bedtime.
- Follow a relaxing bedtime routine. This will help to set aside problems or concerns before bedtime.

Setting the stage

- Turn on a night light
- Use your bed and bedroom for sleeping and sex only.
- Make sure your bedroom is dark, quiet and comfortable.

Do not lie awake in bed for a long period of time. If you cannot sleep, leave your bedroom and do something to help you relax until you fall asleep again.

Conserve Your Energy

- Let other people help you.
- Plan short rest breaks into your work day.
- Spread household tasks throughout the week.
- Wear shirts with front buttons instead of pullovers.
- When cooking, prepare double portions and freeze.
- Wear comfortable clothes and low-heeled, slip-on shoes.
- Choose the tasks that are most important to you perform them when you feel best.
- Whenever you can, sit down to do a task, such as cooking, bathing and drying off, washing dishes or ironing.

Call Your Doctor if:

- You become confused.
- Your fatigue increases over time.
- You are too tired to get out of bed and this feeling lasts 24 hours or more.

Para asistencia en español, por favor llamar al Departamento de Representantes para Pacientes al 312-926-3112.

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Section 4: Tests and Procedures

- Computed Tomography (CT Scan)
- PORT-A-CATH

If you have any questions or concerns about the CT scan, please ask the Radiology staff.

Computed Tomography (CT) Scan

A computed tomography (CT) scan is a special way of looking inside your body. The images produced are cross-sectional planes taken from a part of your body, much like slices taken out of a loaf of bread. The length of the exam will depend upon the area to be scanned and specific information needed by your doctors. The CT scan is done in the Radiology (X-ray) department.

Please tell your doctor or the X-ray staff if you:

- Are pregnant, might be pregnant, are trying to get pregnant or are breastfeeding.
- Are allergic to contrast dye.
- Are on dialysis or have known kidney disease.
- Are diabetic.
- Have had a problem with this exam (or other contrast exams) in the past.

Preparation for the Test

If you have a contrast dye allergy or are taking metformin (Glucophage[®], Glucophage XR[®], Glucovance[®]), you will be given special medication instructions. It is important that you follow these instructions carefully.

For dialysis patients, the CT scan may need to be scheduled on the same day as your dialysis treatment.

Patients over the age of 70 or those having known risk factors may require kidney function tests.

Other preparations for the CT scan will vary depending on the area of the body to be examined. Your doctor will inform you of any needed preparations. These may include:

- Pregnancy testing and advice for withholding breastfeeding.
- Diet restrictions.
- Proper fluid intake.
- Laxatives or bowel preparations.

Patients First

Patients will need to change into a hospital gown for this exam. Outpatients will be shown to a dressing area for changing. You will need to remove any loose or hanging jewelry, such as necklaces. It is not usually necessary to remove rings or watches, but you may choose to do so for comfort.

For certain tests, you may be asked to drink a liquid contrast agent. This oral contrast agent outlines the stomach and bowel on the pictures and will make certain parts of your body appear bright on the pictures. This step is important in obtaining accurate results. If you have any stomach upset or diarrhea, please tell the CT staff.

Another contrast agent, a dye, may be needed during the scan. This is injected through an IV (into the vein) line. This line may be started before the CT scan begins.

During the Test

Before the test begins, the CT staff will explain the test and the equipment used. You will be asked to lie on a table connected to the CT scan machine. The technologist (tech) will line up the part of your body to be examined. The table will then move so that you are in the center of the machine. The tech will keep in contact with you throughout the exam by intercom.

As the exam begins, it is very important that you lie still and follow the instructions of the tech and doctor. The tech may ask you to hold your breath several times during the test.

If needed, a doctor, nurse, or tech will inject the IV contrast. As it is injected, you may feel warm and flushed or feel the urge to urinate. You may also note a metallic taste in your mouth. These are normal effects, although most people will feel nothing at all.

Please tell the staff right away if you note any of the following:

- Shortness of breath.
- Hives.
- Itching.

After the Test

You may resume your normal activities and diet after the test. If you received a contrast agent during the test, it is suggested that you drink an additional 1 or 2 glasses of water. The contrast agent will not discolor your urine. Although it is rare to have any delayed allergic reactions, contact the CT department or your doctor if any rash or swelling occurs.

If you received an oral preparation, you may notice a change in the color and frequency of your bowel movements. If any change lasts more than 2 to 3 days, please contact your doctor.

If you have any questions or concerns about this test, please ask your doctor, nurse or Radiology staff.

Radiation Safety

CT scans use radiation to produce images needed for diagnosis and treatment. There are risks to radiation exposure. It is important to talk with your doctor before having the test to learn about:

- Its risks and benefits.
- The reason for the test.

At Northwestern Memorial Hospital (NMH), we are committed to your safety. This means that your scan will be done with the least amount of radiation without reducing the quality of the exam.

The NMH CT department is proud to be accredited by the American College of Radiology (ACR). Earning this designation ensures that:

- We have undergone a thorough review process.
- Our staff is well qualified, through education and certification to perform and interpret your test results.
- Our equipment is suitable for the test or treatment provided.
- We meet or exceed national quality and safety guidelines.

Health Information Resources

For more information, visit one of Northwestern Memorial Hospital's Health Learning Centers. These state-of-the-art health libraries are located on the third floor of the Galter Pavilion and on the first floor of the Prentice Women's Hospital. Health information professionals are available to help you find the information you need and provide you with personalized support at no charge. You may contact the Health Learning Centers by calling 312-926-LINK (5465) or by sending an e-mail to hlc@nmh.org.

For additional information about Northwestern Memorial Hospital, please visit our Web site at www.nmh.org.

Para asistencia en español, por favor llamar a el departamento de representantes para pacientes al 312-926-3112.

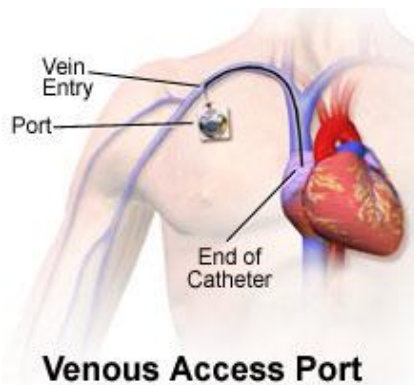
Northwestern Memorial is an equal opportunity employer that welcomes, respects and serves with dignity all people and does not discriminate, including in hiring, or employment, or admission, or access to, or treatment in its programs or activities on the basis of race, color, gender, national origin, religion, disability, handicap, age, Vietnam or other veteran status, sexual orientation or any other status protected by relevant law. To arrange for TDD/TTY, auxiliary aids and foreign language interpretation services, call the Patient Representative department at 312-926-3112, TDD number 312-926-6363. Issues related to the Rehabilitation Act of 1973 should be directed to the director of Employee Relations or designee at 312-926-7297.

Developed by: Department of Radiology

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For more information about Northwestern Memorial Hospital, please visit www.nmh.org.
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PORT-A-CATH

A port-a-cath (also called implanted port or “port”) is a device inserted under the skin on your chest (or sometimes your upper arm). It has a small catheter or tubing attached which is placed into a large vein. When not in use, it will show only as a nickel sized bump underneath your skin. The port is placed by a doctor in the Interventional Radiology department. You will be given some medications to relax and the doctor will use local anesthesia (numbing medicine) where the port is inserted so you will be comfortable. The area may be tender for a few days after the port is placed. You must arrange for a ride home after the procedure as you will be too tired to drive.



The nurse will use a special needle to access the port when it is needed and the needle will be removed when your treatment is completed.

There are many advantages to having a port. It is a safe way to give chemotherapy that could irritate or damage your skin and tissues if it leaked outside of the vein. Some treatments require the patient to go home with a chemotherapy infusion pump and a port will make it easier for you to move about while getting treatment. A port can be used to draw blood as well as receive chemotherapy, IV fluids and other medicines so it will decrease the number of times you have to be “stuck” with a needle. Also a port is a good idea if you have tiny veins that are hard to find.

The port will need to be flushed every month if it is not being used. You can make an appointment with our cancer center nurses to do this if needed.

Section 5: Results

- Lab Results and How to Interpret Them

Lab Results and How to Interpret Them

While you are receiving chemotherapy blood (and sometimes urine) tests will be done on a regular basis—usually the day of your treatment—in order to monitor how your body responds to treatment and to help prevent side effects.

The most common lab tests include:

Complete Blood Count (CBC)

This test measures the different types of blood cells—red blood cells, white blood cells, and platelets. Each of these types of cells has a different job to do in your body and all can be affected by chemotherapy.

Red Blood Cells

Red Blood Cells (RBCs) carry oxygen throughout your body. When levels of healthy red blood cells in the body drop to levels that are below normal, the condition is called anemia. Anemia can occur due to the disease itself, or often related to treatment with chemotherapy agents.

What are symptoms of anemia?

- Dizziness, weakness, or fatigue
- Feeling cold or chilled
- Shortness of breath
- Rapid heart beat
- Sometimes people exhibit no symptoms

What are treatments for anemia?

Your treatment will depend on the cause of your anemia. It will also depend on how severe your symptoms are and the lab value exhibited. Your doctor can tell you more about treatment options and their risks and benefits for you. Treatments include the following:

- **RBC transfusion.** This can reverse anemia very quickly. RBC transfusions are safe. However, there are some risks. Your doctor will discuss them with you. You may need to sign a consent form before receiving treatment.
- **Erythropoiesis stimulating agent (ESA).** This is medication that causes the body to make more RBCs. An ESA is given as a shot. It may be given along with iron (see below). An ESA takes several weeks or months to reverse anemia. There are special risks with ESA treatment. *You may need to sign a consent form before receiving treatment*

White Blood Cells

White Blood Cells (WBCs) fight infection. There are several different types of white blood cells, but the most important infection fighting WBC is the neutrophil. Your nurse and doctor will follow this number closely to determine your risk for infection. If it is low, your doctor may hold or reduce the doses of your treatment.

What is an Absolute Neutrophil Count (ANC)?

You may hear your doctor or nurse talk about your *absolute neutrophil count* or ANC. This is the number of neutrophils you have in a certain amount of blood. Your health care team will use this number to get an idea of how well your immune system might work during treatment.

It's important to watch for early signs of infection and tell your health care team about them right away. This way treatment can be started as early as possible.

Signs and symptoms of an infection might include:

- Body temperature of more than 100.4° F or higher taken by mouth
- Shaking chills or sweats (often goes along with fever)
- Sore throat
- Cough or shortness of breath
- Nasal congestion
- Burning or pain when passing urine; bloody or cloudy urine
- Redness, swelling, drainage, or warmth at the site of an injury, surgical wound, or skin
- Pain or tenderness in the stomach or abdomen (the belly)

Your doctor will check your white blood count often. There's nothing you can personally do to help increase your white blood cell count, but there are some precautions:

- Wash your hands frequently (before and after meals, after using the bathroom, and after sneezing/blowing your nose).
- Avoid anyone who seems to have a cold or is ill with a virus.
- Avoid contact with any children/infants who have recently been vaccinated (within the past 2 weeks).
- Take your temperature at least once a day. **If your temperature is greater than 100.4 call the on-call pager immediately - this is considered an emergency!**
- Cook all meats well and avoid raw meats or fishes. DO drink plenty of fluids.
- Avoid large crowds (i.e., movie theatres, restaurants, etc.).
- Avoid any cleaning activities that would unsettle dust (i.e. vacuuming, sweeping, dusting, etc.).

Platelets

Platelets are the blood cells that help stop bleeding by plugging up damaged blood vessels and helping your blood to clot. If you don't have enough platelets, you may bleed or bruise more easily than usual, even from a minor injury. A shortage of platelets is called *thrombocytopenia*

What are signs of thrombocytopenia?

- Unexpected bruising
- Small flat red spots under your skin
- Red or pink urine (unless you have received adriamycin within the past 24-48 hours)
- Black or bloody bowel movement
- Any bleeding from your gums or nose
- Bad headaches
- Dizziness
- Pain in joints and muscles

Your doctor will check your platelet count often during your treatment. If it falls too low, you may need a platelet transfusion. There is nothing you can do to help increase your platelet count, but there are some **precautions you can take:**

- Do not take medications that interfere with the platelets being able to form a clot
- No aspirin
- No ibuprofen
- Do not use rectal suppositories or taking of your temperature rectally
- Use caution or avoid flossing your teeth
- Use a very soft bristle toothbrush or oral swabs as recommended
- Avoid activities that increase your risk of bleeding when you have low blood platelet count
- Avoid or limit the use of sharp objects such as knives or razors
- Hold pressure on any cut for at least 5-10 minutes
- **Go to the Emergency room immediately if:**
 - Bleeding will not stop after 5-10 minutes of pressure
 - Bleeding that occurs spontaneously (by itself), without injury

Chemistry Panel

This test measures many different things including your sugar (glucose), electrolytes like calcium, potassium, sodium, and magnesium, as well as other substances that can tell us how well your kidneys and liver are functioning. Sometimes you may receive extra hydration or electrolyte repletion.

Ca-125 Tumor Marker

The CA-125 blood test is used to measure the level of CA-125. Elevated levels of CA-125 are often in higher-than-normal amounts in the blood of women with ovarian cancer. Overall, more than 80 percent of women with advanced ovarian cancer will have an elevated CA-125 level (greater than 30 u/ml), yet the test is not useful in detecting early stage disease (approximately 50% accurate). Unfortunately CA-125 is even less reliable for detecting cancer in pre-menopausal women since it is frequently elevated by non-cancerous conditions such as pregnancy, endometriosis, uterine fibroids, liver disease, and benign ovarian cysts. Most gynecologic oncologists employ CA-125 for surveillance of ovarian cancer after the diagnosis has been surgically confirmed since it is a sensitive indicator of persistent or recurrent disease.

Here at Northwestern we measure CA-125 in our patients with ovarian cancer at the beginning of each chemotherapy cycle and then routine follow-up visits. Ideally the CA-125 is elevated when the patient is first diagnosed with ovarian cancer and then decreases to a normal range (<30) after a few cycles of chemotherapy. Once the CA-125 returns to a normal range we follow it at each visit. A subsequent increase of the CA-125 above 30, especially a doubling, prompts a re-evaluation with examination, and possibly CT Scans and PET scan looking for evidence of cancer recurrence.

Section 6: Schedule

- Calendar
- After Visit Summaries (Add your own)

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2016

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Section 7: Supportive Resources

- Supportive Oncology at Northwestern
- Supportive Care and Palliative Medicine
- Caring Advice for Caregivers
- Gilda's Club Chicago
- Look Good...Feel better- American Cancer Society
- Resources in your Community

Supportive Oncology

The strain of being diagnosed and living with cancer can be overwhelming. Many people with cancer experience difficulty. The Supportive Oncology Program provides emotional and practical support for patients and their families at diagnosis, during treatment, and recovery, or at the end of life. Our multidisciplinary team is dedicated to listening and responding to patient concerns, promoting well-being and treating each individual with respect and compassion. Our Supportive Oncology Program works with clinical researchers who conduct clinical trials aimed at improving the psychosocial health of persons with cancer. Common concerns include how to:

- Talk with family, friends and employers about cancer
- Find accurate, trusted health information
- Manage the financial impact of cancer
- Find reliable transportation and lodging
- Cope with appearance-related concerns or challenging emotions
- Care for yourself while juggling treatment with work and family responsibilities
- Plan for life after treatment

Social Workers: Oncology social workers provide psychosocial services to patients, their families and caregivers. Social workers can provide emotional support; help the patient find resources close to home, and assist the patient and family with other practical needs and referrals as they navigate the healthcare system.

| | |
|--|--------------|
| Mary Jo Graden, LCSW, OSW-C, Oncology Social Worker (Women's Cancers) | 312.472.5820 |
| Kristen Huber, LCSW, OSW-C, Oncology Social Worker (Radiation Oncology) | 312.926.4884 |
| Robin Katz, MSW, LSW, Oncology Social Worker (Blood Cancers) | 312.695.8186 |
| Sandra Manley, MSW, LSW, Oncology Social Worker (Solid Tumor) | 312.695.0766 |
| Erica Parr, LCSW, Oncology Social Worker (Hematology Oncology Associates) | 312.981.5525 |
| Lisa Raubolt, LCSW, Oncology Social Worker (Stem Cell) | 312.926.4512 |
| Jessica Voigts, LCSW, Oncology Social Worker (Brain Tumor Institute) | 312.926.5351 |

Clinical Psychologists: Work with patients and family members to manage the stress, and difficult emotions that can often accompany cancer. They also help patients learn strategies to manage physical symptoms such as fatigue, pain, or sleep disturbances. Please call 312.695.0990 to schedule an appointment.

Timothy Pearman, PhD
Nan Rothrock, PhD

Sofia Garcia, PhD
Stacy Sanford, PhD

Susan Yount, PhD

Psychiatry Team: The psychiatry team provides psychiatric evaluation and treatment to patients in need of additional services. They work closely with the clinical cancer care and supportive care teams to manage the unique concerns, medications and symptoms of cancer patients. Lurie Cancer Center patients can be referred by any member of their health care team. Please call 312.695.0990 to schedule an appointment.

Mehmet Dokucu, MD, PhD, Director of Cancer Psychiatry Services
Aimee St Pierre, APN, Psychiatric Nurse Practitioner

Nurse Navigator: Serves as an educator, advocate, liaison, and guide before, during and after treatment, and throughout survivorship. Nurse Navigators can also connect the patient and their family to resources available both in the cancer center or in their community. Currently only certain specialties have a navigator: breast cancer, thoracic cancer and lung cancer.

Lynn Galuska Elsen, RN, BSN

312.472.5821

Mia Guthrie, RN, BSN

312.695.0847

Nutrition Services: Healthy eating is important for everyone, but people with cancer often have special concerns. Registered Dietitians provide up-to-date research-based nutrition advice throughout cancer treatment and into recovery. Please call 312.695.0990 to schedule an appointment.

Stephanie Gagliardo, RD, CDE, LDN (Galter 21 every other W,TR, and F)

312.695.2423

Jocelyn Lutkus RD, CSO, LDN (Galter 21 M, T, and every other W)

312.695.1192

Fertility Preservation Program Navigator: The Patient Navigator for Fertility Preservation is available to all patients in the Lurie Cancer Center who would like more information regarding the impact of treatment on future fertility. The Navigator works with the Lurie Cancer Center physicians as well as reproductive specialists to help patients with fertility concerns before, during and after treatment. Check out preservefertility.northwestern.edu to read more about Fertility Preservation options for patients at Northwestern.

Kristin Smith, Patient Navigator

312.503.3378 or 866.708.FERT

Coordinator of Supportive Oncology Education: The Coordinator of Supportive Oncology Education provides personalized assistance to patients and families seeking information on diagnosis, treatment options, support groups and clinical trials, and offers appropriate referrals to other information sources. She is also involved with outreach and oversight of our volunteer program.

Mariam Eldeib, MSW, LCSW

312.926.7377

Gilda's Club Chicago Hospital Program: Patients and families at the Lurie Cancer Center have on-site access to a wide range of programs offered by Gilda's Club Chicago. All activities are free of charge, and designed to provide knowledge and support while building a community among patients and caregivers.

www.gildasclubchicago.org

Gosha Thornton, AM, LSW – GCC Hospital Program

312.464.9900

Financial Services: Financial counselors are available to help with billing concerns and reimbursement issues, as well as enrollment in financial assistance and free medication programs.

Financial Counseling

312.694.1701

American Cancer Society: The American Cancer Society offers appointments in the Lurie Cancer Center's Healing Boutique for patients who wish to obtain a free wig. To schedule a wig fitting or sign up for a Look Good...Feel Better session, call 312.472.5302. Call their national hotline to get connected to a patient navigator, find discount lodging and connect to other resources.

1.800.227.2345

Advance Directive Experts: Serve as a resource and facilitators to help patients understand what an advanced directive is and help people complete documents such as a Health Care Power of Attorney or Living Will.

312.695.1805

Supportive Care and Palliative Medicine: What is it? How can it help?

What is Palliative Medicine?

Palliative medicine is a specialty that aims to improve quality of life for patients (and their families) living with chronic medical conditions, including cancer. The goals of palliative medicine are the same as those of your oncologists: *to help you cope and live with your cancer, as well as you can, for as long as you can.* Your physician may suggest consultation with a palliative medicine specialist if he or she thinks it could help maintain or improve your quality-of life.

What do Palliative Care practitioners do?

Palliative care teams have specialized training in:

- Cancer-related symptom management, including
 - Cancer- or treatment-related pain
 - Shortness of breath
 - Nausea, vomiting, or loss of appetite
 - Fatigue or Difficulty sleeping
- Anxiety or Depression related to living with cancer and undergoing treatment
- Advance care planning (thinking about living with your illness, helping you make decisions about your care, and making plans for your future)

Who is part of the Palliative Care Team?

Physicians, nurse-practitioners, and nurses who will work in collaboration with your oncology physicians and nurses.

When is the Right Time for Consultation with the Palliative Care Team?

At any point that you, your family, or your doctors feel that you may need help with your symptoms or coping with your illness. Feel free to call **312-926-0001** to discuss your questions.

Is Palliative Care the Same as Hospice?

No. Palliative care can be part of the care plan for any patient with a chronic illness, no matter what the prognosis may be. Patients can (and often do) receive anti-cancer therapy and palliative care at the same time. The goal is to help you live as well as you can, for as long as you can. The goals of hospice are the same – helping you live as well as you can – but hospice is more for patients who no longer want or cannot tolerate anti-cancer therapy.

Will Palliative Medicine Consultation be covered by Insurance?

Your Palliative Medicine consultation will be billed separately from your oncologist's visit. *Most insurance plans, including Medicare, cover Palliative Medicine consultations as part of your overall care.* You may need to pay an additional co-payment. Please ask the clinic staff if you have any questions.



CANCERcare®

800-813-HOPE (4673)
info@cancercaare.org
www.cancercaare.org

fact sheet

CARING ADVICE FOR CAREGIVERS: HOW CAN YOU HELP YOURSELF?

Caregivers are individuals who provide emotional and physical care for a person with cancer. Being a caregiver can be a full-time job, and caregivers often put their own needs or feelings aside while caring for their loved one. Taking good care of yourself is an important part of being a caregiver. This can improve your quality of life and help you to be better equipped to handle your caregiving responsibilities.



HERE ARE SOME TIPS FOR TAKING CARE OF YOURSELF WHEN YOU'RE A CAREGIVER:

Organize help.

Decide which of your loved one's needs you can or would like to meet on your own, and which ones you need help with. Then, ask family members, friends, neighbors, co-workers or professionals to share the care. Ideally, many people will want to help. Realistically, only one or two people may be available. Still, these individuals can make a big difference. Check with community agencies, religious institutions or a hospital social worker for information on volunteer and respite care programs.

Join a support group for caregivers.

Support groups help many caregivers feel less alone. They provide a safe, supportive environment for sharing feelings and discussing the challenges and rewards of being a caregiver. Group members provide a listening ear and share tips and resources they've learned along the way. CancerCare offers free, professionally led, face-to-face, telephone and online support groups for caregivers.

Become informed.

Learn about your loved one's diagnosis and treatment so you have a sense of what to expect. With your loved one's permission, you may want to speak to the doctor or nurse if you have any concerns. He or she can recommend resources for learning more and getting support. Find out who else on the health care team (such as an oncology social worker, oncology nurse or pharmacist) is available to help you if you have any questions.

Understand your rights.

Under the Family and Medical Leave Act, most employers are required to provide up to 12 weeks of unpaid, job-protected leave for family members who need time off to care for a loved one. For help with insurance rules and regulations, contact your insurance company. Many insurance companies will assign a case manager to address concerns, clarify benefits and suggest ways to obtain additional health-related services.

(over)



CancerCare® Can Help

Founded in 1944, CancerCare is the leading national organization providing free support services and information to help people manage the emotional, practical and financial challenges of cancer. Our comprehensive services include counseling and support groups over the phone, online and in-person, educational workshops, publications and financial and co-payment assistance. All CancerCare services are provided by professional oncology social workers.

To learn more, visit www.cancercare.org or call **800-813-HOPE (4673)**.

Facebook: facebook.com/cancercare

Twitter: @cancercare

Keep up with your own check-ups, screenings and medications.

Your health is very valuable. Stay on top of your doctor appointments, and find a good system for remembering to take any medicines you need to stay healthy.

Get individual help.

As a caregiver, you may sometimes feel overwhelmed and need more than friends or family members to talk to. Speaking with a counselor or social worker can help you cope with some of the emotions or concerns you may be facing. CancerCare provides free individual counseling from oncology social workers who specialize in helping people with cancer and their loved ones and caregivers.

Do something good for yourself.

Take a few moments for yourself each day to do something enjoyable or relaxing, even if it's just taking a walk around the block. Give yourself credit for all you do as a caregiver, and find ways to reward yourself for your hard work.

This fact sheet has been made possible by educational donations from: Genentech, a Member of the Roche Group; Lilly; and Amgen.



CANCERcare®

National Office • 275 Seventh Avenue • New York, NY 10001

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GILDA'S CLUB CHICAGO

AT THE LURIE CANCER CENTER

Galter Pavilion 21

675 N. St Clair

"COME AS YOU ARE" YOGA : This class, led by a certified yoga instructor, is designed for beginners and those with physical challenges, or for those who just want a gentle stretching class. This activity may be done seated in a chair or standing.

TUESDAYS: 9:30AM-10:30AM Galter 21

T'AI CHI CHIH® : T'ai Chih Chih promotes joy through movement with a modern technique based on ancient Chinese wisdom and 19 simple and slow gentle movements. T'ai Chi Chih is a mix of meditation and movement that has been shown to reduce stress. It can be done while sitting or standing and is fun to learn! For all ages and physical conditions. No special clothing required.

Facilitator: Deb Sitron, Licensed LMT & Board Certified NCBTMB

WEDNESDAYS: 9:30AM-10:30AM Galter 21

CRAFTS: Relax by engaging in a crafty project. Activities include beading, tracing, and painting. Supplies provided. All skill levels are welcome. **Facilitator: Lindsey Newman, BFA, Art Instructor**

TUESDAYS: 10:30AM-12:00PM Galter 21

KNITTING: Explore the wonderful world of handcrafted fibers as you learn how to knit in the European style!

THURSDAYS: 10:00AM-11:00AM Galter 21

ART AS RELAXATION: Learn origami and be surprised by the sense of accomplishment after making your first paper crane. Other art projects may also be featured.

WEDNESDAYS: 9:30AM-11:00AM Galter 21



JEWELRY MAKING: Here you will learn ways to create original accessories like earrings, necklaces, bracelets and more! The classes will offer an atmosphere of learning and support for those seeking to be creative.

THURSDAYS: 9:30AM-11:00AM Galter 21

Prentice Women's Hospital

250 E. Superior

JOURNAL WRITING can be a form of mediation and stress relief, while at the same time allowing the individual to express themselves and explore their creative side. This group will teach journal writing techniques and will give participants a chance to share their writing with others.

THURSDAYS: 11:00AM-12:00 PM P5

SPIRITUAL AWAKENINGS: A weekly space for patients, families, and staff to enjoy 30 minutes of music, meditation, or inspirational literary works. Each Thursday holds something special and be sure not to miss the second Thursday of the month when we feature something extra-special! Stop by to rejuvenate, relax, and restore!

THURSDAYS: 11:15AM-11:45AM PWH Chapel 3rd Floor

Become a member of Gilda's Club Chicago to be a part of our community of support. Our free membership is available to any adult or child whose life has been touched by cancer.

Available by request 312-464-9900, Wednesdays: 11:00AM 12:00PM

ARTIST- IN - RESIDENCE: PWH 14th, 15th and 16th floors

Do you remember the pleasure you had making art as a child? Relax by painting, drawing, and tracing. An art instructor is going from room to room with art supplies and suggestions.

ART AS RELAXATION: Galter 21 and PWH In the Infusion Clinics

An art instructor is going from room to room with art supplies and suggestions. Learn and be surprised by the sense of accomplishment after making your own art.





look good **feel better**
HELPING WOMEN WITH CANCER

**The Latest Cancer Treatments
Aren't Always Prescribed by Doctors
Please join us for**

Look Good...Feel Better®

A FREE workshop that teaches beauty techniques to women who are actively undergoing cancer treatment, to help them combat the appearance-related side effects of radiation and chemotherapy.

Look Good Feel Better Schedule

4th Monday of the month: 10:00 am to 12:00 pm

2nd Wednesday of the month 4:00pm to 6:00pm

To find a program in your neighborhood check out:

lookgoodfeelbetter.org/programs



Wig Program

Free wigs offered to women who have experienced hair loss due to the effects of chemotherapy and radiation. By appointment only.

Location:

**Prentice Women's Hospital
5th Floor, Suite 520, Supportive Oncology**

To register or to make an appointment: Call 312-472-5302

RESOURCES IN YOUR COMMUNITY

The Chicagoland area has community support centers that offer services to patients and their loved ones FREE of charge. These organizations offer programs tailored to everyone effected by Cancer, focusing on caregivers, men, children and providing education and support in all areas.

Cancer Wellness Center: Northbrook / Grayslake

Ovarian Cancer: 2nd Wednesday monthly from 7:00pm-8:30pm

Wellness House: Hinsdale

Gynecological Cancers: 2nd Thursday of the month from 7:00-8:30pm

The Cancer Support Center: Homewood / Mokena

Gynecological Cancers Networking Group: 3rd Wednesday of each month 4:00pm-5:30pm

Gilda's Club Chicago

Ovarian Wellness: 1st and 3rd Tuesday of the month at 6:00pm

Living Well: Geneva

Gynecological Cancer Networking Group: 1st Monday of the month from 7:00pm-8:30p,

Online Support Group: CancerCare

Gynecological and Ovarian Cancer Patient Group

SUPPORT ORGANIZATIONS

| | | |
|--|---------------------|--------------------------------------|
| Cancer Care | 800.813.HOPE (4673) | Cancercare.org |
| Cancer and Careers | 646.929.8023 | cancerandcareers.org |
| Culinary Care | 847.781.0955 | culinarycare.org |
| Imerman Angels | 877.274.5529 | imermanangels.org |
| NeedyMeds | 978.865.4115 | needymeds.org or goodrx.com |
| National Ovarian Cancer Coalition | 888.682.7426 | ovarian.org |
| Foundation for Women's Cancer | 312.578.1439 | foundationforwomenscancer.org |

CREDIBLE HEALTH INFORMATION

| | | |
|---|--------------|---------------------------|
| American Cancer Society | 800.227.2345 | cancer.org |
| American Society of Clinical Oncology | 888.651.3038 | cancer.net |
| National Cancer Institute | 800.4.CANCER | cancer.gov |
| National Institute of Health - Clinical Trials | | clinicaltrials.gov |
| National Library of Medicine | 888.FIND.NLM | medlineplus.gov |
| National Coalition for Cancer Survivorship | 877.622.7937 | canceradvocacy.org |
| National Comprehensive Cancer Network | 866.788.NCCN | nccn.org/patients |

Section 8: Personal Documents

- Survivorship Care Plan
- Voice in Your Future
- Power of Attorney Document



Society of Gynecologic Oncology Survivorship Summary

Ovarian Cancer Treatment Summary and Survivorship Care Plan

For

Patient Name: _____

DOB: ___/___/___

MR Number: _____

Cancer Treatment Team:

Gynecologic Oncologist: _____ Contact Info: _____

Radiation Oncologist: _____ Contact Info: _____

Medical Oncologist: _____ Contact Info: _____

Navigator / Social Worker: _____ Contact Info: _____

Post-Treatment Care Team:

Primary Care Provider: _____ Contact Info: _____

Cancer Surveillance Provider: _____ Contact Info: _____

Cancer History (any):

Personal: _____

Family: _____

Genetic referral: no yes (results) _____ Date: _____

Ovarian Cancer Diagnosis and Treatment Summary:

Date of Diagnosis: ___/___/___

Stage: _____

Histology: _____ Grade: _____

CA-125 at diagnosis: _____

Initial Surgery: no yes on ___/___/___ (specify, procedure(s), significant pathology):

Debulking: Optimal Suboptimal Residual disease size: _____ Location: _____

Chemotherapy: no yes (specify drugs, route, doses, number of cycles):

Chemotherapy start date: ___/___/___ completion date: ___/___/___

Clinical trial participation: yes no Details of Clinical Trial: _____

Date of Completion of Primary Therapy (i.e., surgery and chemotherapy): ___/___/___

Toxicity of treatment: _____

Disease Status at Completion of Primary Therapy:

Complete Clinical Response / No Evidence of Disease Other: _____



Persistent Treatment-Associated Adverse Effects at Completion of Therapy

It is important to recognize that not every woman experiences the following adverse events after treatment. You may not have any of these issues, a few or many adverse effects. Experiences are highly variable. Please discuss any adverse effects of cancer treatment with your cancer care team.

After SURGICAL THERAPY

Menopausal symptoms: Hot flashes, night sweats and vaginal dryness may occur. See your health care professionals about non-medication recommendations and medication-based treatment.

Leg swelling: Minimal to pronounced lower leg swelling can occur. Symptom control with compression hose, lymphedema massage or specialized physical therapy can be ordered.

Sexual intimacy issues: Vaginal dryness and scarring at the top of the vagina causing discomfort can occur. Use of a lubricant and dilator can help prevent or improve vaginal symptoms.

After CHEMOTHERAPY

Numbness and tingling of extremities: Symptoms may worsen in the months after surgery and then may improve. Medications and acupuncture are treatment options.

After Cancer Treatment in General: It is not uncommon for cancer to impact other areas of your life such as relationships, work and mental health. If you develop financial concerns, resources are sometimes available to assist in these areas. Depression and anxiety can present either during or after cancer diagnosis and treatment. It is important to discuss with your physician any of these concerns so these resources can be made available to you.

Social Worker: _____

Local Ovarian Cancer Support Group and Contact Information: _____

Financial Counselor and Contact Information: _____

Dietician Contact Information and Information Provided: _____

Society of Gynecologic Oncology Recommendations

Self Care Plan: What You Can Do to Stay Healthy after Treatment for Ovarian Cancer

Cancer treatments may increase your chance of developing other health problems years after you have completed treatment. The purpose of this self care plan is to inform you about what steps you can take to maintain good health after cancer treatment, including coping with side effects of treatment, reducing the risk of cancer returning, and watching for signs of cancer returning or of a new cancer. Keep in mind that every person treated for cancer is different and that these recommendations are not intended to be a substitute for the advice of a doctor or other health care professional. Please use these recommendations to talk with your doctor and health care team about an appropriate follow-up care plan for you.

Recommendation for Follow-Up for Ovarian Cancer

Have a medical history and physical exam that is focused on detecting signs of cancer recurrence or of new cancers, including a detailed pelvic exam (speculum, pelvic and rectovaginal; however, a routine Pap smear is not recommended for routine cancer follow up). Frequency depends on stage of cancer and other risk factors. For instance, if you had a higher stage of cancer, you may be seen more often. See the table below for general guidelines.

If you had ovarian cancer once, there is a chance that it may come back or spread to other parts of your body. The risk is highest in the first two to three years after treatment, but continues for at least five years. After five years, it is recommended that you have a careful history and physical including pelvic exam (check-up) every 12 months for the rest of your life.

After cancer treatment, if you feel that something is not right with your body, see your regular doctor, physician assistant or nurse practitioner. Symptoms to report to your health care team include abdominal distension, feeling full easily, new and persistent nausea and vomiting, bloating, vaginal bleeding, rectal bleeding, weight loss without effort, new and persistent pain, new and persistent fatigue, new masses (i.e., bumps in your neck or groin), new and persistent cough and any other concerns. If what you are feeling is urgent, and you cannot get an appointment with your regular health care team, go to an Urgent Care or Medical Walk-In Clinic. Tell the medical provider you had cancer. Show them a copy of your ovarian cancer treatment summary.

Ovarian cancer surveillance recommendations

| Variable | Months | | | Years | |
|---|--|--|--|--|--|
| | 0-12 | 12-24 | 24-36 | 3-5 | >5 |
| Review of symptoms and physical examination | Every 3 mo | Every 3 mo | Every 4-6 mo | Every 6 mo | Yearly ^a |
| Papanicolaou test/ cytologic evidence | Not indicated | Not indicated | Not indicated | Not indicated | Not indicated |
| Cancer antigen 125 | Optional | Optional | Optional | Optional | Optional |
| Radiographic imaging (chest x-ray, positron emission tomography/ computed tomography, magnetic resonance imaging) | Insufficient data to support routine use | Insufficient data to support routine use | Insufficient data to support routine use | Insufficient data to support routine use | Insufficient data to support routine use |
| Recurrence suspected | Computed tomography and/or positron emission tomography scan | Computed tomography and/or positron emission tomography scan | Computed tomography and/or positron emission tomography scan | Computed tomography and/or positron emission tomography scan | Computed tomography and/or positron emission tomography scan |
| | Cancer antigen 125 | Cancer antigen 125 | Cancer antigen 125 | Cancer antigen 125 | Cancer antigen 125 |

^a May be followed by a generalist or gynecologic oncologist.

Salani. Surveillance for gynecologic cancers. *Am J Obstet Gynecol* 2011.

Voice in Your Future

Who Will Speak for Me? A Voice in Your Future: Your Health, Your Decision

At Northwestern Memorial Hospital, we honor your right to make your healthcare wishes known. The Illinois Power of Attorney for Healthcare was created so that you have a voice in your medical treatment even if you are unable to speak for yourself. The law allows you to complete a Power of Attorney for Healthcare to designate someone to make healthcare decisions if you cannot.

For any of us, the time may come when an accident or illness leaves us temporarily unconscious or otherwise unable to make decisions. The time may come when no medical treatment will restore our physical health. Because this can happen to anyone, we encourage everyone to designate a decision maker.

It is easy to complete a Power of Attorney for Healthcare:

- There is no cost.
- You do not need a lawyer.
- You can prepare it at home or at the hospital.

The Power of Attorney for Healthcare allows you to name a person to act as your “agent” to make decisions on your behalf when you cannot do so.

Your Agent Acts for You Only When You Cannot Make Your Own Decisions.

You can appoint any adult as your agent, except a healthcare provider involved in your care. Most people appoint a trusted family member or friend. Before you appoint an agent, we recommend that you ask the person if they are willing to make decisions on your behalf and make certain they understand your wishes about the kind of medical treatment you want. You can have only one agent, but it is a good idea to list “successor” agents in case the first person you choose is unavailable.

The agent’s role is to make healthcare decisions for you.

- You may give your agent all the powers that you would normally have and the power to consent to, or refuse, any type of healthcare.
- You can place limitations on your agent’s power or can give your agent specific rules to follow.
- If you have registered to be an organ donor in Illinois (donatelifeillinois.org), your agent does not have to make this decision. If you have not registered, your agent would have to make that decision.

The standard form of the Power of Attorney for Healthcare contains blanks for you to fill in, if you choose, with instructions for your agent. It also contains three statements about life-sustaining treatment. You can select the statement that is closest to your own intentions or you can write your own. If you decide to write your own, we recommend you discuss it with your physician to be sure that it reflects your own medical situation.

Facts About the Power of Attorney for Healthcare

- You may use a standard form or you may write your own.
- The form does not need to be prepared by a lawyer.
- The form does not need to be signed by a physician. However, we encourage you to discuss your thoughts and preferences with your physician to make sure that your form reflects the choices you want.
- The form is free and you can find it at www.nmh.org/nm/hospital-guide-advance-directives, in our Health Learning Center, on the State of Illinois website at idph.state.il.us/public/books/advin.htm or by asking a chaplain, social worker or patient representative at Northwestern Memorial.
- If you used a form from another state that meets the Illinois legal requirements, we will honor it.

How Do I Prepare a Power of Attorney for Healthcare?

While you are a patient, the hospital staff can assist you in completing the Power of Attorney for Healthcare. In the hospital's Health Learning Center, you can find educational videos and other resources about advance directives.

What Do I Do With the Power of Attorney for Healthcare When I Complete It?

Give copies to your primary care physician, your hospital physician and close family members or friends. If you are admitted to the hospital, we will scan the documents into your electronic medical record so they are available to the clinical team.

We encourage you to talk with your physicians, family and friends about how you want to be cared for if you can no longer speak for yourself. It is especially important to discuss the kind of treatment you would like to receive if you have a terminal condition or are unable to make your own decisions for an extended period of time. We also encourage you to talk to a trusted physician who knows you well as you think about these issues.

Consider:

- Do you believe that sometimes the burden and pain of treatment might be greater than the benefit?
- Do you have special concerns or questions about artificial ventilation, tube feedings or other kinds of treatment administered when you are terminally ill?
- Do you have any special concerns about pain or comfort care? Your physicians and nurses will always provide pain management and comfort care along with other care and treatment according to your needs and preferences.

If you complete a Power of Attorney for Healthcare and later change your mind, you can revoke the document by tearing it up or stating that it is being revoked. Each time you are admitted to the hospital, we will ask you if we have the most current copy.

Other Advance Directives

There are other forms of advance directives that some patients may wish to use.

- The Do Not Resuscitate (DNR) order is helpful to patients nearing the end of life who do not want any attempts made at CPR (cardiopulmonary resuscitation), including shocks attempting to restore heartbeat and support of breathing by a tube placed in the windpipe and attached to a breathing machine (ventilator). While you are in the hospital, your physician can enter an order so that CPR is not attempted. Patients with a DNR order may still receive the full range of other necessary medical treatment, including pain management and comfort care, medication, therapy, dialysis and sometimes even surgery.

If you want to have this order available even when you are at home, the State of Illinois has a form you may use at idph.state.il.us/public/books/advin.htm or you can ask for it at the hospital. This order must be signed by the patient and a physician. If you bring this order to the hospital, it will be honored. If you would like to prepare one before you go home from the hospital, we will assist you.

- A Mental Health Treatment Preference Declaration lets you say whether you consent to receive electroconvulsive treatment, psychotropic medicine or admission to a mental health facility when you have a mental illness. You may name someone to make decisions about mental health treatment if you are incapable. A form is available at idph.state.il.us/public/books/advin.htm.

If You Do Not Specify a Decision Maker

If you decide not to designate an agent and if you cannot make your own decisions, under Illinois law, a limited range of healthcare decisions will be made by your legal “surrogate,” in this order of priority:

1. Court-appointed guardian (if any)
2. Spouse
3. Adult child
4. Parent
5. Adult brother or sister
6. Adult grandchild
7. Close friend
8. Court-appointed guardian of the estate

If more than one family member is in the same category, the majority must make the decision. For example, if there are three adult children, at least two must agree. In making healthcare decisions, the family members or friends must try to come to the same decision that the patient would have. However, a surrogate under Illinois law does not have the same authority or decision-making power that an agent has under the Power of Attorney for Healthcare.

We recommend that everyone complete a Power of Attorney for Healthcare to be sure that your wishes will be followed.

Hospital Resources

We encourage you to discuss any questions about your care and treatment with your personal physician and the other physicians, nurses and caregivers who care for you during your hospital stay. The following individuals also are on staff at Northwestern Memorial and available to assist:

Chaplains

312-926-2028

Patient Representatives

312-926-3112

For More Information:

Alberto Culver Health Learning Center

Northwestern Memorial Hospital
Galter Pavilion
Third floor
312-926-5465

Northwestern Memorial Hospital

www.nmh.org
Download Advance Directives forms under the Hospital Guide tab by clicking on “Patient Stay & Care.”

Illinois Department of Public Health

idph.state.il.us/public/books/advin.htm

Register as an Organ Donor in Illinois

donatelifeillinois.org

If you need assistance, feel free to ask your nurse, chaplain, social worker or patient representative.



251 East Huron Street
Chicago, Illinois 60611-2908
312.926.2000
nmh.org

OUR MISSION

Northwestern Memorial is an academic medical center hospital where the patient comes first. We are an organization of caregivers who aspire to consistently high standards of quality, cost-effectiveness and patient satisfaction. We seek to improve the health of the communities we serve by delivering a broad range of services with sensitivity to the individual needs of our patients and their families. We are bonded in an essential academic and service relationship with Northwestern University Feinberg School of Medicine. The quality of our services is enhanced through their integration with education and research in an environment that encourages excellence of practice, critical inquiry and learning.



The entities that come together as Northwestern Medicine are committed to representing the communities we serve, fostering a culture of inclusion, delivering culturally competent care, access to treatment and programs in a nondiscriminatory manner and eliminating healthcare disparities. For questions, please call the Northwestern Memorial Hospital Patient Representatives department at 312-926-3112, TDD/TTY 312-944-2358 and/or the Northwestern Medical Group Patient Representatives Department at 312-926-1920, TDD/TTY 312-695-3661.

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Dear Patient,

In this packet you will find a copy of the official State of Illinois “**POWER OF ATTORNEY FOR HEALTH CARE.**”

We invite all patients to complete this form, so that you can tell us who can speak for you if there is ever a time when you cannot speak for yourself.

When you complete this form, you are choosing one person who will have all the same power you would have to make decisions for yourself, if there is ever a time when you cannot make them.

If you don't use a Power of Attorney document, then Illinois state law determines who can speak for you as your “surrogate.” However, a health care surrogate's power to make decisions may be very limited in certain situations. For example, a health care surrogate cannot tell your health care providers to withdraw or withhold life-sustaining treatment unless you have certain “qualifying conditions.” You may want these limits, or you may not.

If you want to be specific in choosing **who** will make decisions for you, and **what limits** there should be on those decisions, then the Power of Attorney for Health Care is the best way to make your wishes known.

Hospital staff are available to help you complete this form if you wish. Please ask your nurse to contact a chaplain, social worker, or patient representative. We encourage you to discuss this subject with your doctor and your family as well. A witness to your signature is required by law. Information on who may and may not serve as a witness to your signature is found at the end of the Power of Attorney document.

We will store this document with your medical record. However, we will ask you for the document at each visit or admission, because it is important for your care that we have the most recent one readily accessible. Please bring it every time you come to NM for care.

Thank you for taking time to plan so that you receive the care that is right for you.

ILLINOIS STATUTORY SHORT FORM POWER OF ATTORNEY FOR HEALTH CARE

NOTICE TO THE INDIVIDUAL SIGNING THE POWER OF ATTORNEY FOR HEALTH CARE

No one can predict when a serious illness or accident might occur. When it does, you may need someone else to speak or make health care decisions for you. If you plan now, you can increase the chances that the medical treatment you get will be the treatment you want.

In Illinois, you can choose someone to be your “health care agent.” Your agent is the person you trust to make health care decisions for you if you are unable or do not want to make them yourself. These decisions should be based on your personal values and wishes.

It is important to put your choice of agent in writing. The written form is often called an “advance directive.” You may use this form or another form, as long as it meets the legal requirements of Illinois. There are many written and on-line resources to guide you and your loved ones in having a conversation about these issues. You may find it helpful to look at these resources while thinking about and discussing your advance directive.

WHAT ARE THE THINGS I WANT MY HEALTH CARE AGENT TO KNOW?

The selection of your agent should be considered carefully, as your agent will have the ultimate decision-making authority once this document goes into effect, in most instances after you are no longer able to make your own decisions. While the goal is for your agent to make decisions in keeping with your preferences and in the majority of circumstances that is what happens, please know that the law does allow your agent to make decisions to direct or refuse health care interventions or withdraw treatment. Your agent will need to think about conversations you have had, your personality, and how you handled important health care issues in the past. Therefore, it is important to talk with your agent and your family about such things as:

- (i) What is most important to you in your life?
- (ii) How important is it to you to avoid pain and suffering?
- (iii) If you had to choose, is it more important to you to live as long as possible, or to avoid prolonged suffering or disability?
- (iv) Would you rather be at home or in a hospital for the last days or weeks of your life?
- (v) Do you have religious, spiritual, or cultural beliefs that you want your agent and others to consider?
- (vi) Do you wish to make a significant contribution to medical science after your death through organ or whole body donation?
- (vii) Do you have an existing advance directive, such as a living will, that contains your specific wishes about health care that is only delaying your death? If you have another advance directive, make sure to discuss with your agent the directive and the treatment decisions contained within that outline your preferences. Make sure that your agent agrees to honor the wishes expressed in your advance directive.

WHAT KIND OF DECISIONS CAN MY AGENT MAKE?

If there is ever a period of time when your physician determines that you cannot make your own health care decisions, or if you do not want to make your own decisions, some of the decisions your agent could make are to:

- (i) Talk with physicians and other health care providers about your condition.
- (ii) See medical records and approve who else can see them.
- (iii) Give permission for medical tests, medicines, surgery, or other treatments.
- (iv) Choose where you receive care and which physicians and others provide it.
- (v) Decide to accept, withdraw, or decline treatments designed to keep you alive if you are near death or not likely to recover. You may choose to include guidelines and/or restrictions to your agent's authority.
- (vi) Agree or decline to donate your organs or your whole body if you have not already made this decision yourself. This could include donation for transplant, research, and/or education. You should let your agent know whether you are registered as a donor in the First Person Consent registry maintained by the Illinois Secretary of State or whether you have agreed to donate your whole body for medical research and/or education.
- (vii) Decide what to do with your remains after you have died, if you have not already made plans.
- (viii) Talk with your other loved ones to help come to a decision (but your designated agent will have the final say over your other loved ones).

Your agent is not automatically responsible for your health care expenses.

WHOM SHOULD I CHOOSE TO BE MY HEALTH CARE AGENT?

You can pick a family member, but you do not have to. Your agent will have the responsibility to make medical treatment decisions, even if other people close to you might urge a different decision. The selection of your agent should be done carefully, as he or she will have ultimate decision-making authority for your treatment decisions once you are no longer able to voice your preferences. Choose a family member, friend, or other person who:

- (i) is at least 18 years old;
- (ii) knows you well;
- (iii) you trust to do what is best for you and is willing to carry out your wishes, even if he or she may not agree with your wishes;
- (iv) would be comfortable talking with and questioning your physicians and other health care providers;
- (v) would not be too upset to carry out your wishes if you became very sick; and
- (vi) can be there for you when you need it and is willing to accept this important role.

WHAT IF MY AGENT IS NOT AVAILABLE OR IS UNWILLING TO MAKE DECISIONS FOR ME?

If the person who is your first choice is unable to carry out this role, then the second agent you chose will make the decisions; if your second agent is not available, then the third agent you chose will make the decisions. The second and third agents are called your successor agents and they function as back-up agents to your first choice agent and may act only one at a time and in the order you list them.

WHAT WILL HAPPEN IF I DO NOT CHOOSE A HEALTH CARE AGENT?

If you become unable to make your own health care decisions and have not named an agent in writing, your physician and other health care providers will ask a family member, friend, or guardian to make decisions for you. In Illinois, a law directs which of these individuals will be consulted. In that law, each of these individuals is called a “surrogate.”

There are reasons why you may want to name an agent rather than rely on a surrogate:

- (i) The person or people listed by this law may not be who you would want to make decisions for you.
- (ii) Some family members or friends might not be able or willing to make decisions as you would want them to.
- (iii) Family members and friends may disagree with one another about the best decisions.
- (iv) Under some circumstances, a surrogate may not be able to make the same kinds of decisions that an agent can make.

WHAT IF THERE IS NO ONE AVAILABLE WHOM I TRUST TO BE MY AGENT?

In this situation, it is especially important to talk to your physician and other health care providers and create written guidance about what you want or do not want, in case you are ever critically ill and cannot express your own wishes. You can complete a living will. You can also write your wishes down and/or discuss them with your physician or other health care provider and ask him or her to write it down in your chart. You might also want to use written or online resources to guide you through this process.

WHAT DO I DO WITH THIS FORM ONCE I COMPLETE IT?

Follow these instructions after you have completed the form:

- (i) Sign the form in front of a witness. See the form for a list of who can and cannot witness it.
- (ii) Ask the witness to sign it, too.
- (iii) There is no need to have the form notarized.
- (iv) Give a copy to your agent and to each of your successor agents.
- (v) Give another copy to your physician.
- (vi) Take a copy with you when you go to the hospital.
- (vii) Show it to your family and friends and others who care for you.

WHAT IF I CHANGE MY MIND?

You may change your mind at any time. If you do, tell someone who is at least 18 years old that you have changed your mind, and/or destroy your document and any copies. If you wish, fill out a new form and make sure everyone you gave the old form to has a copy of the new one, including, but not limited to, your agents and your physicians.

WHAT IF I DO NOT WANT TO USE THIS FORM?

In the event you do not want to use the Illinois statutory form provided here, any document you complete must be executed by you, designate an agent who is over 18 years of age and not prohibited from serving as your agent, and state the agent's powers, but it need not be witnessed or conform in any other respect to the statutory health care power.

If you have questions about the use of any form, you may want to consult your physician, other health care provider, and/or an attorney.

MY POWER OF ATTORNEY FOR HEALTH CARE

THIS POWER OF ATTORNEY REVOKES ALL PREVIOUS POWERS OF ATTORNEY FOR HEALTH CARE.

(You must sign this form and a witness must also sign it before it is valid.)

My name (print your full name): _____

My address: _____

I WANT THE FOLLOWING PERSON TO BE MY HEALTH CARE AGENT
(an agent is your personal representative under state and federal law):

(Agent name) _____

(Agent address) _____

(Agent phone number) _____

MY AGENT CAN MAKE HEALTH CARE DECISIONS FOR ME, INCLUDING:

- (i) Deciding to accept, withdraw, or decline treatment for any physical or mental condition of mine, including life-and-death decisions.
- (ii) Agreeing to admit me to or discharge me from any hospital, home, or other institution, including a mental health facility.
- (iii) Having complete access to my medical and mental health records, and sharing them with others as needed, including after I die.
- (iv) Carrying out the plans I have already made, or, if I have not done so, making decisions about my body or remains, including organ, tissue or whole body donation, autopsy, cremation, and burial.

The above grant of power is intended to be as broad as possible so that my agent will have the authority to make any decision I could make to obtain or terminate any type of health care, including withdrawal of nutrition and hydration and other life-sustaining measures.

I AUTHORIZE MY AGENT TO (please check any one box):

- Make decisions for me only when I cannot make them for myself. The physician(s) taking care of me will determine when I lack this ability.

(If no box is checked, then the box above shall be implemented.) **OR**

- Make decisions for me starting now and continuing after I am no longer able to make them for myself. While I am still able to make my own decisions, I can still do so if I want to.

The subject of life-sustaining treatment is of particular importance. Life-sustaining treatments may include tube feedings or fluids through a tube, breathing machines, and CPR. In general, in making decisions concerning life-sustaining treatment, your agent is instructed to consider the relief of suffering, the quality as well as the possible extension of your life, and your previously expressed wishes. Your agent will weigh the burdens versus benefits of proposed treatments in making decisions on your behalf.

Additional statements concerning the withholding or removal of life-sustaining treatment are described below. These can serve as a guide for your agent when making decisions for you. Ask your physician or health care provider if you have any questions about these statements.

SELECT ONLY ONE STATEMENT BELOW THAT BEST EXPRESSES YOUR WISHES (optional):

- The quality of my life is more important than the length of my life. If I am unconscious and my attending physician believes, in accordance with reasonable medical standards, that I will not wake up or recover my ability to think, communicate with my family and friends, and experience my surroundings, I do not want treatments to prolong my life or delay my death, but I do want treatment or care to make me comfortable and to relieve me of pain.
- Staying alive is more important to me, no matter how sick I am, how much I am suffering, the cost of the procedures, or how unlikely my chances for recovery are. I want my life to be prolonged to the greatest extent possible in accordance with reasonable medical standards.

SPECIFIC LIMITATIONS TO MY AGENT’S DECISION-MAKING AUTHORITY:

The above grant of power is intended to be as broad as possible so that your agent will have the authority to make any decision you could make to obtain or terminate any type of health care. If you wish to limit the scope of your agent’s powers or prescribe special rules or limit the power to authorize autopsy or dispose of remains, you may do so specifically in this form.

My signature: _____

Today’s date: _____

HAVE YOUR WITNESS AGREE TO WHAT IS WRITTEN BELOW, AND THEN COMPLETE THE SIGNATURE PORTION:

I am at least 18 years old. (Check one of the options below):

- I saw the principal sign this document, or
- The principal told me that the signature or mark on the principal signature line is his or hers.

I am not the agent or successor agent(s) named in this document. I am not related to the principal, the agent, or the successor agent(s) by blood, marriage, or adoption. I am not the principal’s physician, mental health service provider, or a relative of one of those individuals. I am not an owner or operator (or the relative of an owner or operator) of the health care facility where the principal is a patient or resident.

Witness printed name: _____

Witness address: _____

Witness signature: _____

Today’s date: _____

SUCCESSOR HEALTH CARE AGENT(S) (optional):

If the agent I selected is unable or does not want to make health care decisions for me, then I request the person(s) I name below to be my successor health care agent(s). Only one person at a time can serve as my agent (add another page if you want to add more successor agent names):

(Successor agent #1 name, address and phone number)

(Successor agent #2 name, address and phone number)