



# Treatment Guide





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# Section 1: Welcome

- Who does what?
- Supportive Care and Palliative Medicine





### Your Health Care Team: Gastrointestinal

## Who Does What?

A multidisciplinary team is a group of different specialists that work together to determine the best treatment plan for you and your cancer. During your initial workup and at times throughout your therapy, the team may review information and diagnostic tests together to determine the best course of therapy for you. The multidisciplinary team involved in treating your specific cancer often includes:

#### **Medical Oncologist**

A doctor who specializes in treating cancer with chemotherapy and other anticancer medications.

Al B Benson III MD
 Mary Mulcahy MD
 Sheetal Kircher MD

#### **Medical Oncology Fellow**

A doctor who has completed residency and is specializing in medical oncology. A fellowship is three years of intensive training. Each fellow rotates through the clinic in six month increments. There is a different fellow for each day of clinic. You will often see a fellow in conjunction with your medical oncologist.

#### **Nurse Practitioner**

A nurse practitioner (NP) is an advanced practice registered nurse (APN) who had completed additional training beyond that of a registered nurse. NP's conduct physical exams, diagnose and treat illnesses, order and interpret tests, counsel in health care, and write prescriptions. The NP will work closely with your medical oncologist.

Bridget O'Brien APN
 Marcia Mickle APN
 Marian Tentler APN
 Vicki Pressling APN

#### Nursing

Provides many services including administering chemotherapy and supportive medications, providing patient education, assessing for side effects and collaborating with the oncology team regarding symptom management.

O Caroline Castino BSN RN O Kirztie Silverman BSN RN

#### **Nurse Coordinator**

Serves as a patient liaison and provides many services including providing patient education, assessing for side effects, collaborating with the oncology team regarding symptom management, arranging appointments with the other oncology disciplines, and communicating with the other oncology team members with updates and concerns

Shareea Graham BSN RN

#### **Clinical Research Nurse**

Clinical research coordinators work under the study's principal investigator- your oncologist. The nurse will screen patients, explain the study, and schedule your appointments. The coordinator keeps accurate records of your adverse effects or positive benefits of treatment and sends paperwork to the required facilities sponsoring the study.

#### **Medical Assistant**

Assists you in your appointments in the laboratory, clinic, and infusion areas. Brings you to your exam or infusion room and will take your vital signs and weight.

#### **Patient Service Representative**

Schedules your future appointments and diagnostic testing, ensures you complete any orders written by the physician or NP, and prints an after visit summary for the appointment

Katrina White (or her colleagues in the area)

#### **Financial Counselors**

Help with billing questions, concerns about insurance coverage

Kristy Patruno

#### **Social Worker**

Provides individual and family counseling in the following areas: emotional adjustment to illness and treatment, relaxation techniques, learning skills and strategies that may help you to come to terms with treatment and medical care, talking with loved ones, helping children cope with a family member's illness, support for grief and losses. Helps link to resources based on need: support groups, help at home, financial resources, help with prescription costs, employment rights, vocational rehabilitation, transportation and accommodation resources, and advance directives. Your physician may refer you to a social worker if they assess you need it or if you initiate a request.

Sandra Manley, LSW

#### **Registered Dietician**

Works specifically with cancer patients and understand the unique needs associated with cancer and undergoing chemotherapy. Provides recommendations for nutritional status improvement.

- Stephanie Gagliardo, RD, CDE, LDN (Galter 21 every other W,TR, and F)
- Jocelyn Lutkus RD, CSO, LDN (Galter 21 M, T, and every other W)
- Mary Reher, MS, RDN, LD (Prentice)

#### **Psychologist**

Specializes in anxiety, depression, insomnia, and other psychological needs specific to patients with cancer and their families. Your healthcare team may refer you to see the psychologist if a need is assessed or at your request.





# 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;
  - o 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 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 play for <u>any</u> 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.





# **Section 2: Diagnosis**

• NCCN Guidelines for Patients

# NCCN Guidelines for Patients®

Patient-friendly translations of the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®)



- Caring for Adolescents and Young Adults (AYA)
- Chronic Myelogenous Leukemia
- Colon Cancer\*
- Esophageal Cancer
- Lung Cancer Screening
- Malignant Pleural Mesothelioma\*
- Melanoma\*
- Multiple Myeloma\*
- Non-Small Cell Lung Cancer\*
- Ovarian Cancer
- Pancreatic Cancer\*

- Prostate Cancer
- Stage 0 Breast Cancer\*
- Stages I & II Breast Cancer\*
- Stage III Breast Cancer\*
- Stage IV Breast Cancer\*

\* Printed copies available.

### Available online at NCCN.org/patientguidelines!



The NCCN Guidelines for Patients® are supported by charitable donations made to the NCCN Foundation®



**DONATE NOW** nccnfoundation.org

NCCN National Comprehensive Cancer Network\*



NCCN Patient Education Webinar Know What Your Doctors Know: Non-Small Cell Lung Cancers

Access recorded webcast by visiting NCCN.org/patients





# **Section 3: Tests and Imaging**

- Lab Tests and What They Mean
- Computed Tomography (CT Scan)
- Magnetic Resonance Imaging
- Bone Scan
- Position Emission Tomography (PET/CT) Scan
- Colonoscopy





#### LAB TESTS AND WHAT THEY MEAN

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 watch 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 (RBCs) carry oxygen throughout your body. If these are too low it is called anemia and you may feel more tired or short of breath.
- 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 your treatment or reduce the doses.
- Platelets help to stop bleeding. You may bruise easily if this number is low. Your doctor may also hold your treatment or reduce the dose if it is too low.

#### **Chemistry panel**

Blood chemistry tests measure many different things including sugar (glucose), electrolytes like calcium, potassium, sodium and magnesium and other substances that can tell us how well your kidneys and liver are working. Sometimes we will have to give you extra fluid or replace your electrolytes. The doctor may make a change in your treatment or dose based on these results.

#### **Urine tests**

Some chemotherapy drugs can affect your kidneys. You may be asked to give a urine specimen which will be checked for protein or blood so we can be sure it is safe for you to receive the medications.

#### **Tumor Markers**

Tumor markers are substances that may be found in the blood, urine or tissues of some patients with cancer. They are proteins made by normal cells as well as cancer cells but may be made at higher levels when you have cancer. The levels of tumor markers can be used to check how you are responding to your treatment or if cancer has returned. It may be

checked periodically throughout treatment by taking a blood test. Common tumor markers that we use include:

- CEA (carcinoembryonic antigen) May be found in blood with colorectal, pancreas, or breast cancer.
- CA 19-9 May be found in blood with pancreas, gallbladder, gastric or bile duct cancer
- AFP (alpha-fetoprotein) May be found in blood with liver cancer
- Chromogranin A: May be a useful marker for neuroendocrine tumors

Some newer types of tumor markers are checked by looking at the tumor cells that were removed during surgery. These can help determine treatment options for you. Some of these are:

- Her2/Neu.: This marker is found in your tissue sample from biopsy or surgery. It is checked with gastric, esophageal, or breast cancer to see if treatment with herceptin (trastuzumab) is right for you.
- KRAS / BRAF: These markers are also found in your tissue sample. It is checked with colorectal cancers to determine if treatment with certain targeted therapies is right for you.
- MSI: This marker, which can be checked in your tumor tissue sample, provides information about your tumor type and may suggest treatment options.



#### **Patient Education**

**TESTS AND PROCEDURES** 

# 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.

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

#### **Preparation for the Test**

If you have a contrast dye allergy or are taking metformin (Glucophage<sup>®</sup>, Glucophage XR<sup>®</sup>, Glucovance<sup>®</sup>), 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



#### Patient Education

**TESTS AND PROCEDURES** 

### **Magnetic Resonance Imaging (MRI)**

A magnetic resonance imaging (MRI) exam is a special way of looking inside your body. It is different from an X-ray. It uses a magnetic field and radio waves to create the pictures. During the test, a contrast agent (dye) may be given. This makes certain parts of your body appear brighter on the pictures.

If you have any questions about this test, please call the MRI
Department at

312-926-9000

The exam time depends upon the area to be scanned and the information needed by your doctors. Most exams last about 45 to 60 minutes. The MRI is done in the Radiology (X-ray) Department. Northwestern Memorial Hospital offers the option of 4 locations:

- Feinberg Pavilion at 251 E. Huron St.
- **441** E. Ontario St.
- 1913 W. North Ave. in Chicago's Bucktown neighborhood.
- Prentice Women's Hospital at 250 E. Superior St.

#### **Before the Test**

Please tell your doctor if you might be pregnant, are trying to become pregnant or are breastfeeding.

Also, please notify your doctor if you are on dialysis or have known kidney disease. If you are on dialysis, you will need to schedule dialysis on the day of your MRI, as well as the following day. This helps rid the body of any contrast dye used during the MRI exam.

Every MRI patient will be screened to ensure that certain safeguards are in place. Please tell your doctor or MRI staff before the exam if you have any metal inside your body. This may include:

- Pacemaker
- Aneurysm clip
- Ear or eye implant
- Joint or bone rods or clips
- Metal plate
- Bullets or shrapnel

Patients First

It is also helpful to talk with your doctor if you:

- Cannot lie flat for about an hour.
- Have claustrophobia (are uncomfortable with closed-in spaces).

Please ask your doctor if you need to make any changes in your diet before this exam. Otherwise, there is no special preparation for this test.

On the day of the test, plan to arrive 30 minutes before your test time. Also, be sure to bring:

- Your doctor's written order for the test.
- A list of all your current medications (prescription and over-the-counter).
- Medical insurance information.
- Medicare card (Medicare patients only).

If plans were made to give you any medicine to help you relax, you also will need a responsible adult to take you home. Also, there are special diet instructions. The scheduling MRI staff will discuss these with you before the exam.

Upon arrival, you will be asked to complete an MRI safety questionnaire and a medical history form.

Prior to the test, you will be taken to a locker room to change into a hospital gown and store your belongings. It is important that you remove all metal, including jewelry, credit cards, keys and dentures. The staff nurse then reviews your completed forms with you. An IV (into the vein) line is started in your arm or hand.

### **During the Test**

Once you are taken into the exam room, you are introduced to the technologist (tech) and nurse who will perform the test. They can answer any questions you may have.

You are asked to lie on a table attached to the MRI machine. The nurse and tech help position you comfortably on the exam table. You are given a hand-held device to help you contact the tech during the test as needed. Ear plugs also are provided. If medication to relax you was ordered, it is injected into the IV at this time. You may be given an IV contrast agent (gadalinium dye) during the test. As the dye is injected, you may feel warm or flushed or you might notice a metallic taste in your mouth. This is normal. However, please notify the staff right away if you have shortness of breath, hives or itching.

Your body and the machine are lined up so that the proper area of your body can be examined. Then the table moves so that you are in the center of the machine. The tech keeps in contact with you throughout the exam. During the MRI, you will hear a loud drumming noise. It is very important that you lie still and follow instructions. Between scans, the drumming noise stops. You may be asked to hold your breath several times during the test.

When the exam is over, you will be assisted off the exam table.

#### **After the Test**

If relaxing medication was given, you must remain in the department for about an hour. Your blood pressure, heart rate, and oxygen level will be monitored by a nurse. Unless told otherwise, you may resume your normal activities and diet after the exam. It is helpful to drink extra fluids if a contrast agent was given. The contrast agent does not discolor your urine.

Most often, initial findings are sent to your doctor within 48 hours. A full report follows in about 5 business days.

#### **Health Information Resources**

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#### **Patient Education**

**TESTS AND PROCEDURES** 

#### **Bone Scan**

Your doctor has ordered a bone scan that can show early bone disease. In many cases, the test can detect this condition before it can be seen on standard X-rays. A bone scan uses a small amount of radioactive material (tracer) that is absorbed into the bones. The amount of radiation used in this test is small, and well within limits that are not considered harmful. Your total test time is about 4 hours.

Please tell your doctor or the Nuclear Medicine staff if you may be pregnant or if you have had a problem with this exam in the past.

#### **Before the Test**

There is no special preparation for the test. On the day of the test, please come to the 8th Floor reception desk in the Galter Pavilion, 201 E. Huron St., at your scheduled appointment time. Parking is available for patients and visitors in the garage at 222 E. Huron, across from the Feinberg and Galter Pavilions. For discounted rates, please bring your parking ticket with you. Tickets can be validated at the Customer Services Desks on the 1st, 2nd and 8th floors of the Feinberg and Galter Pavilions, and the 1st floor of Prentice (including the Prentice 24-hour desk near the Superior St. entrance).

Be sure to bring:

- Your doctor's written order for the test.
- A list of allergies.
- A list of all your current medications (prescription, overthe-counter, and herbals).
- Photo ID.
- Medical insurance information.
- Medicare card (Medicare patients only).

#### **During the Test**

When you arrive in the Nuclear Medicine department, a nuclear technologist (tech) will ask you questions about your medical history. If you think you might be pregnant or are breastfeeding, please tell the tech before you are given any injection.

You will then be given an IV (into the vein) injection of radioactive tracer. The tech will ask you to return to the Nuclear Medicine department about 2 to 4 hours later. This time is needed for the tracer to localize into your bones. When you return, the scan will take about 1 to 2 hours. You will be asked to empty your bladder. This is done so that the pelvic and hip bones will show up clearly. You will then be asked to lie down on a table and a total body image will be taken. A doctor will review your bone scan and, in most cases, will ask for extra images to obtain more detailed information

#### **After the Test**

You may resume your normal activities and diet. The injection you were given is not harmful and will become non-radioactive within hours. Talk with your doctor about your test results. You may obtain a copy of your results at Medical Records on the 2nd floor of the Galter Pavilion.

If you have any questions about this test, please call the Nuclear Medicine Department at 312-926-2320, Monday through Friday, 7:30 a.m. to 5:00 p.m.

#### **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.

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Developed by: Department of Nuclear Medicine



#### Patient Education

**TESTS AND PROCEDURES** 

# Positron Emission Tomography (PET/CT) Scan

PET/CT is a scan that reveals the size, shape and position of the organs. It also shows how well certain organs are working. First, a small dose of radioactive sugar is injected into your vein. Then, a special camera is used to generate an image for a doctor to read. This entire exam takes about 2 hours and is done in the Nuclear Medicine Department.

The radioactive sugar used in your scan is ordered just for you

Please call us at 312-926-3762 at least 24 hours in advance if you need to

cancel your

appointment.

The radioactive sugar used in your scan is ordered just for you and your appointment. It must be destroyed if not used. For this reason, we ask for at least 24 hours notice if you need to change or cancel your appointment.

This brochure provides important information about how to prepare for and what to expect during your scan.

#### **Before Your Test**

If you have had a recent MRI or CT at another hospital, please plan to bring the records to the appointment. The Nuclear Medicine doctor will need to compare these prior tests with your PET scan. If you need to get these records after your PET scan is done, your PET scan results may be delayed.

Please tell us if you:

- Are taking steroids. These medicines may raise your blood sugars to levels too high to do the scan. Also let us know about any other medicines/herbals you are taking.
- Think you might be pregnant.
- Are currently breastfeeding. There are special guidelines you will need to follow.

Talk to your doctor who ordered the exam if you have:

- A history of anxiety.
- Claustrophobia.
- Pain while lying down.

Patients First

Medicine may be prescribed to make you more comfortable during the scan. If you will be taking medicine to relax, you will need a responsible adult to take you home after the scan.

#### At Home:

- Do not exercise for **24 hours before** your scan.
- Do not eat or drink 4 hours before your scan. This includes food, flavored water, chewing gums and mints. Unflavored water, bottled or tap, is fine.
- Do not take insulin within 4 hours before your appointment. You may take diabetic pills with regular water.

Please plan to arrive 15 minutes before your appointment time. Be sure to bring:

- Your doctor's written order for the test.
- A list of all your current medicines (prescription and over-the-counter, herbals).
- Medical Insurance information.
- Medicare card (Medicare patients only).
- Recent MRI or CT reports and scans (from other hospitals/clinics).

#### Arrival:

*Please come* to Nuclear Medicine department, 8th floor in Northwestern Memorial Hospital's Galter Pavilion, 251 East Huron Street.

Parking is available for patients and visitors in the garage at 222 East Huron, across from the Feinberg and Galter Pavilions. For discounted rates, please bring your parking ticket with you. Tickets can be validated at the customer service desks on the 1st and 2nd floor of the Feinberg and Galter Pavilions.

You will need to remove any loose or hanging jewelry, such as necklaces, rings or watches. You will need to remove any change or any other metal objects you might have in your pockets.

**The tech** will check you blood sugar by pricking your finger. An IV (into the vein line) will be placed into your arm or hand.

A small dose of radioactive sugar is injected into your IV. Then you will be asked to rest quietly in a room for one hour after the injection. You may watch TV listen to music, or read. Please do not talk, text message or write.

**During the Exam:** Once you are in the exam room, a nurse or technologist will assist you in lying on a table connected to the PET/CT machine. You will lie on your back with your arms over your head. For about the next 30 minutes, a series of "pictures" will be taken by the PET/CT machine.

#### After the Exam:

If you have taken medicines to relax you or for pain, you will need a responsible adult to take you home. You may resume your normal activities after the test unless you are told otherwise by your doctor. A doctor called a radiologist or **Nuclear Medicine physician** will review your test and notify your doctor of the results. If you have any questions about the test, please call the Nuclear Medicine department at **312-926-3762**.

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#### **Patient Education**

**TESTS AND PROCEDURES** 

### Colonoscopy

A colonoscopy is an exam used to detect disease of the lower digestive tract for early signs of colon and rectal cancer. This includes polyps, which can, over time, develop into cancer. It also is helpful in finding the cause of diarrhea, bleeding or changes in bowel habits.

The test, done in the GI Lab, takes about 30 minutes. But your total time in the lab is about  $2\frac{1}{2}$  to 3 hours. During the exam, a small flexible tube is inserted into the rectum and to the colon. At the end of the tube is a tiny video camera with a light. This test may be more helpful than X-rays alone since the doctor may:

- Actually view the area.
- Remove polyps.
- Take a small tissue sample (biopsy).

The colon must be fully emptied so the doctor can view the area. Depending on the exam time and your needs, the bowel prep may vary. Your doctor will give you specific written instructions. Follow these bowel prep guidelines carefully. Be sure to obtain this instruction sheet from your doctor. Your doctor will give a *Patient Questionnaire* form and *Patient Medication List* to you to complete and bring with you on the day of the exam.

If you have any questions please call your doctor's office or the GI Lab, 312-926-7614

#### **Before the Test**

#### 14 Days Before the Test

Talk with your doctor about your routine medicines. It is important to tell the doctor if you:

- Are on any "blood-thinning" medicines such as anticoagulants, aspirin, non-steroidal anti-inflammatory drugs (NSAIDs).
- Are taking an iron supplement.
- Are a diabetic or have problems with low blood sugar.
- Take antibiotics prior to certain medical procedures.
- Have an implantable cardioverter defibrillator (ICD).

Patients First

Blood thinning medications and iron supplements are often stopped 7 days before the colonoscopy. Diabetics need to follow their doctor's guidelines for how to adjust oral medications and insulin.

#### 7 Days Before the Test

Follow your doctor's guidelines on how to take:

- Iron supplements.
- Anticoagulants or prescribed blood thinners.
- Any medications containing aspirin.
- NSAIDs including ibuprofen (Advil®, Motrin®.)

If you are unsure about the medicines included in these groups, ask your doctor or pharmacist. Acetaminophen (Tylenol®) may be taken for minor pain.

Purchase the bowel prep (NuLytely<sup>®</sup>, Suprep<sup>®</sup>, Moviprep<sup>®</sup>) ordered by your doctor. These are found at most drug stores.

#### Day Before the Test

Refer to your doctor's instruction sheet for your specific prep including:

- Liquid diet guidelines.
- Bowel prep (NuLytely®, Suprep®, Moviprep®.)

If you have any questions, please call your doctor's office or you may contact the Gastrointestinal (GI) Lab patient care coordinator at 312-926-7614.

#### Day of the Test

Unless told otherwise, take all routine medicines (except blood thinners, aspirin, NSAIDs) on the morning of your exam with sips of water. Follow your doctor's diet guidelines. Remember, sips of water are allowed until 3 hours before the exam.

It is helpful to wear loose, comfortable clothes on the day of the exam. Be sure to bring the completed *Patient Questionnaire* form and *Patient Medication List* and plan to have a responsible adult to take you home after the exam.

Please arrive at the GI Lab 30 minutes before your test. It is located at the Galter Pavilion, 201 E. Huron St. Take the elevators to the 4th floor and go to the front desk check-in area.

Parking is available for patients and visitors in the garage at 222 E. Huron, across from the Feinberg and Galter Pavilions. For discounted rates, please bring your parking ticket with you. Tickets can be validated at the Customer Services Desks on the 1st and 2nd floor of the Feinberg and Galter Pavilions; 1st floor of Prentice (including the Prentice 24 hour desk near the Superior St. entrance).

After changing into a hospital gown, an IV (into the vein) line will be inserted into your hand or arm. The IV is used for giving medicine during the exam. The doctor will explain the exam and answer any questions you may have. You will be asked to sign a written consent.

#### **During the Exam**

Before the test begins, the nurse helps you lie on an exam table on your left side. Medicine to relax you is injected into the IV. Once the medicine starts working, the doctor slowly inserts the colonoscope in your rectum to the large intestine. Pictures of the lining of the colon can be seen on a TV monitor.

If polyps or abnormal tissue are noted, a biopsy may be done. A thin wire or looped device is inserted into the colonoscope to remove a tissue sample or the entire polyp. (This is not painful.) If bleeding is found in the colon, a small laser probe or medicine can be used to stop the bleeding.

During the exam, you may feel bloating. This is due to the air used to expand the folds of the colon for easier viewing. You may also have some cramps as the colonoscope moves through the curves of the large intestine. Medicine is given through the IV to relieve this discomfort and to relax you. Your blood pressure, heart rate, respiratory rate and oxygen level will be checked often.

#### **After the Exam**

The nurse will check on you often for at least 1 hour after the exam while the medicine wears off. The nurse will ask you to lie on your left side to allow you to pass gas. This also helps relieve any cramping and bloating. Due to the limited space, there is no visiting in the recovery area. Please let us know about any special visiting needs.

The medicine given during the test affects your judgment and reflexes. You may feel groggy. Do not drive or operate machinery until the next day. You must have a responsible adult accompany you home, or the test will be rescheduled.

Unless you are otherwise instructed, you may resume your diet and routine medicine after you leave the GI Lab. You also will be given written guidelines before you leave.

#### Test Results

The doctor or nurse will discuss the exam results with you or your family on the day of the test. A follow-up doctor's visit to go over your exam and biopsy results may be needed. Biopsy results are usually ready 5 to 7 days after your test.

#### When to Call the Doctor

After the exam, you may notice a small amount of blood in your bowel movements. This is normal. However, contact your doctor if you have:

- Severe abdominal pain.
- A fever above 100.5° F.
- Chills.
- Significant rectal bleeding.

If you have any questions about this test, please contact your doctor or the GI Clinic at 312-695-5620.

#### **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.

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

Para asistencia en español, por favor llamar al 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, or for issues related to the Rehabilitation Act of 1973, call the Patient Representative Department at 312-926-3112, TDD/TTY number 312-926-6363.





# **Section 4: Treatment Regiment**

- PORT-A-CATH
- Clinical Trials





### **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.





### **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 <a href="http://cancer.northwestern.edu/clinicaltrials/index.cfm">http://cancer.northwestern.edu/clinicaltrials/index.cfm</a>
- 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.

#### 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.







# **Section 5: Side Effect Management**

Side Effects and How to Manage Them





### 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:

#### **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 of 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 2 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
- If you are receiving Oxaliplatin you will likely be sensitive to the cold for a few days after treatment. You may feel tingling or burning in your fingers/ hands if you touch something cold or walk barefoot on a cold floor. Cold foods may tingle when you swallow them or feel like they are stuck.
- 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.
   If you are on Oxaliplatin, make sure you bundle up when it is cold—wear hat, gloves, and scarf with a warm coat. Use gloves or pads to protect your hands when getting something form the refrigerator or freezer. Let cold foods come to room temperature before eating especially for the first 3 to 5 days after treatment.

#### **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 will 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!)

#### **Fertility**

Some types of chemotherapy can affect your ability to get pregnant or father a child. You should talk this over with your doctor before starting treatment. There are ways to preserve your eggs or sperm to use after treatment ends. It is very important that you do not become pregnant or father a child while on chemotherapy as these drugs can harm the baby. Talk to your doctor about safe forms of birth control for you.

You can still have sex while on chemotherapy but use a barrier method of protection (condom) to protect your partner from exposure to the drugs.

Some people may have less interest in sex while on treatment due to fatigue and anxiety, while others may have an increased desire. It is important to talk with your partner about your feelings and concerns. We also have a supportive oncology team of psychologists and social workers who can help you sort through your feelings. Just ask your nurse or doctor to help you set up an appointment.





### **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 byproducts. 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/mm<sup>3</sup>. 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**

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. 900854 (01/14)





### **Section 6: Supportive Resources**

- Supportive Oncology
- Diet and Nutrition
- Resources in your Community
- Gilda's Club Chicago
- Look Good...Feel Better-American Cancer Society
- Integrative Medicine
- Voice in your Future
- Power of Attorney Document





### **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

<u>Social Workers:</u> 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.

Robin Katz, MSW, LSW, Oncology Social Worker (Blood Cancers)	312.695.8186
Sandra Manley, MSW, LSW, Oncology Social Worker (Solid Tumor)	312.695.0766
Oncology Social Worker (Radiation Oncology)	312.926.4884
Erica Parr, LCSW, Oncology Social Worker (Hematology Oncology Associates)	312.981.5525
Jessica Voigts, LCSW, Oncology Social Worker (Brain Tumor Institute)	312.926.5351
Crystal Ward, MSW, LSW, Oncology Social Worker (Women's Cancers)	312.472.5820

<u>Clinical Psychologists:</u> 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 Sofia Garcia, PhD Susan Yount, PhD Nan Rothrock, PhD Stacy Sanford, PhD Linda Emanuel, MD, PhD

<u>Psychiatry Team:</u> 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

<u>Nurse Navigator:</u> 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 and 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

<u>Nutrition Services:</u> 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)312.695.2423Jocelyn Lutkus RD, CSO, LDN (Galter 21 M, T, and every other W)312.695.1192Mary Reher, MS, RDN, LD (Prentice)312.472.5823

**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

<u>Gilda's Club Chicago Hospital Program:</u> 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.

Gosha Thornton, AM, LSW – GCC Hospital Program

312.464.9900

<u>Financial Services</u>: 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

<u>Pastoral Services and Education:</u> Chaplains tend to a patient's emotional, social, and spiritual aspects of healing. You may contact Pastoral Services from 8 a.m. to 5 p.m., Monday through Friday. You can ask a healthcare professional to page a chaplain if you need assistance.

312.926.2028





### 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.
wheat germ (23 call rusp)	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):
  - o 1 oz. cheese, 1 slice toast
- peanut butter and jelly sandwich (555 cal):
  - o 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):
  - o 1 egg, 1 oz. cheese, and 1 English muffin
- natural peanut butter and banana on toast (350 cal):
  - o 2 Tbsp natural peanut butter, 1 banana, 1 slice of toast
- granola and yogurt (500 cal):
  - o 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.





### 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. For additional programs you can check out Gilda's Club Chicago, Living Well Cancer Resource Center in Geneva and Cancer Resource Centre in Munster Indiana.

Cancer Wellness Center: Northbrook / Grayslake

Pancreatic Cancer Group – 2<sup>nd</sup> Thursday monthly from 5:30-7:00pm

**Wellness House: Hinsdale** 

Colon Cancer Networking Group: 2<sup>nd</sup> Monday monthly from 6:30-8:00pm

Pancreatic Cancer: 2<sup>nd</sup> Thursday monthly from 7:00pm-8:30pm

The Cancer Support Center: Homewood / Mokena

Colon Cancer Networking Group: 1st Monday of the month 6:30-7:30pm

**Online Support Group: CancerCare** 

Colorectal Cancer Patient Group
Pancreatic Cancer Caregiver Group

### **SUPPORT ORGANIZATIONS**

Chris 4 Life Colon Cancer Foundation	855.610.1733	chris4life.org
Colon Cancer Alliance	877.422.2030	ccalliance.org
Cancer Care	800.813.HOPE (4673)	Cancercare.org
Cancer and Careers	646.929.8023	cancerandcareers.org
The Cholangiocarcinoma Foundation	801.999.0455	cholangiocarcinoma.org
Cancer Legal Resource Center	866.843.2572	CancerLegalResourceCenter.org
Culinary Care	847.781.0955	culinarycare.org
Debbie's Dream Foundation:		debbiesdream.org
Fight Colorectal Cancer	877.427.2111	fightcolorectalcancer.org
Imerman Angels	877.274.5529	imermanangels.org
LIVESTRONG Foundation	855.220.7777	livestrong.org
Life Matters Media	773.269.8685	lifemattersmedia.org
NeedyMeds	978.865.4115	needymeds.org
Pancreatic Cancer Action Network (PanCAN)	877.272.6226	pancan.org
<b>United Ostomy Association of Chicago</b>		uoachicago.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







### Gilda's Club Chicago at the Lurie Cancer Center

### Galter Pavilion, 21<sup>st</sup> Floor, 675 North St. Clair Street, Chicago, IL 60611

"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

**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

**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

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

THURSDAYS: 10:00AM-11:00AM

**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

**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

### Prentice Women's Hospital, 250 East Superior Street, Chicago, IL 60611

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 5<sup>th</sup> Floor

**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 Chapel 3rd Floor

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





### **American Cancer Society: Look Good Feel Better**

# 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

4<sup>th</sup> Monday of the month: 10:00 am to 12:00 pm 2<sup>nd</sup> 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 5<sup>th</sup> Floor, Suite 520, Supportive Oncology

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

### M Northwestern Medicine®

Osher Center for Integrative Medicine 150 East Huron, Suite 1100 Chicago, IL 60611

Osher Center for Integrative Medicine (OCIM) primary care and other covered services as indicated below will be billed directly to insurance. For other providers below, we will bill named participating plans after verification of benefits. Other patients will be asked to pay at time of service. Out-of-network insurance may be billed only with pre-authorization.

Integrative Medicine	Integrative Medicine physicians emphasize the relationship between the doctor and patient, by focusing on the innate healing ability of the body and the importance of addressing all aspects of an individual's life to attain optimal health and healing. Dr. Ring and Dr. Stracks will work with your primary care provider and a team of complementary and alternative medicine practitioners to help you achieve <i>optimum wellness</i> , not just freedom from your current health problems.	Melinda Ring, MD John Stracks, MD
Internal /Family Medicine (Primary Care Providers)	The OCIM primary care team includes internists and advance practice nurses who coordinate all of your conventional health care. OCIM providers use the most up-to-date approaches to diagnosis and treat diseases. Our providers are open to incorporating complementary approaches, and take a preventive, holistic approach to your health.  These providers accept the same plans as NMPG Internal Medicine. Please see the Accepted Insurance Plans list for NMPG Internal Medicine for details.	Sharon Vocino, MD Shibani Munshi, MD Mary Anne Meyer, CNP
Acupuncture /Traditional Chinese Medicine & Herbology	OCIM acupuncturists are considered in-network for BCBS PPO only. We will bill BCBS subject to verification of benefits. All other patients will be asked to pay at time of service.  Nambudripad's Allergy Elimination Techniques also known as NAET®, are noninvasive, drug free, natural solutions to eliminate allergies of all types and intensities using a blend of selective energy balancing, testing and treatment procedures from acupuncture/acupressure, chiropractic, nutritional, and kinesiological disciplines of medicine.	Ania Grimone, MS, Lac  Average fees: Initial and Intake \$130 F/U \$90 Herbs (price varies) Cosmetic initial \$160 Cosmetic f/u \$120 Laser additional \$25 Electro-stim additional \$10
Chiropractic	OCIM Chiropractic participates in the following managed plans: Aetna BCBS PPO, Blue Edge& Blue Advantage PPO (not Blue Choice Select PPO) BCBS Classic Blue HMO (groups 467 or 466) Cigna Galaxy / MCI Medicare (Initial visit is paid at time of service.) Unicare HMO & PPO  We do not participate in United, PHCS or Humana chiropractic networks. Medicaid is not accepted for Chiropractic services scheduled after June 30, 2012. HMO & POS plans may require referral from your PCP.	Mindy Cramer, DC, CCEP, DACO
Massage Therapy	OCIM massage therapy is considered in-network only for BCBS PPO. Massage therapy done as part of chiropractic visits can be billed to the same insurance as the chiropractic visit, subject to confirmation of benefits. All other patients will be asked to pay at time of service.	Chris Wilson, LMT Kathryn Lee, LMT Aline Silberg, LMT(Lakeview) Average fee: 30 min \$60 60 min \$120 90 min \$180

### M Northwestern Medicine®

### Osher Center for Integrative Medicine 150 East Huron, Suite 1100 Chicago, IL 60611

Health Psychology	OCIM health psychologists participate in the following managed care plans.  Aetna HFN  BCBS PPO & BlueEdge Health Marketing Inc  BCBS Blue Advantage PPO Humana Choice Care  (not Blue Choice Select PPO) Magellan  BCBS Classic Blue Medicare  (PCP groups 467 or 466) Multiplan  Beech Street PHCS  CCN ppoNext  Galaxy / MCI Preferred Network Access (PNA)  Great-West Preferred Plan Inc (PPI)  Unicare  For plans not listed, we ask patients to pay at time of service.	Howard Feldman, PhD Maggie Crowley, PsyD Helene Moore, PsyD
Functional Nutrition – Naturopathic Practitioner	Doctors of Naturopathic medicine (N.D.'s) receive extensive training in basic medical sciences and graduate from four-year accredited institutions. Doctors of Naturopathic Medicine focus on therapies that are primarily natural in origin and non-toxic, such as functional nutrition, homeopathy, botanical medicine, hydrotherapy, physical therapy and counseling.  Doctors of naturopathic medicine are not licensed physicians or registered dieticians. While some states license naturopathic doctors, the State of Illinois currently does not. Judy Fulop is ineligible to participate in Medicare, Medicaid (IL HFS), or any of our insurance contracts.	Judy Fulop, MS, ND  Average fee: Initial \$220 F/U \$75 - \$105 Phone Consult \$50 Per 15 min.  Nutrition only: \$105 Flu/Cold visit: \$105  Supplements (price varies)
Nutrition - Registered Dietitian	Through our supervising physicians, registered dietitian services are considered innetwork for the same insurances as NMPG Internal Medicine. See Accepted Insurance list for Internal Medicine for details. Medicare only covers Diabetes or Renal failure diagnoses and must have a physician referral.  Exception: Dietitian services are not covered by Medicaid (IL HFS).	Michele Scott, RD, CDE  Average fee: \$134.40  Resting Metabolic Rate (RMR) testing: \$149  Diabetes 101 Group Class: \$49
Tobacco Cessation	The OCIM Tobacco Cessation Program is based on proven methods, which represent the most current thinking in cessation effort. Led by a registered nurse with over 25 years of experience helping people quit using tobacco, you will find our services are designed to fit your unique needs. We ask all patients to pay at time of service.	Carol Southard, RN, MSN Average individual fee: Initial \$175 F/U \$87.50 Group sessions: \$250/8 weeks (Call 312-926-8400 to schedule group sessions





### **Survivorship Resources**

After you have completed your treatment, it is common to have mixed emotions. Although you are relieved to have active treatment behind you, many patients worry about what will happen next and miss the close contact they had with their health care team. You have special needs at this time and it is important that you feel that all your needs are being met.

Ask your doctor about these changes or what to expect regarding your:

✓ Physical Needs

✓ Emotional Needs

✓ Day –to-Day Concerns

**Body Changes** Lifestyle

**Body changes and Intimacy Memory and Concentration** 

Changes in weight and eating habits Menopause symptoms

**Fatigue** Neuropathy

Changes in bladder or bowel function **Pain or Swelling** 

### Organizations that can provide credible information and support:

**American Cancer Society** 800.227.2345 **The Survivorship Center** 800.227.2345 **National Cancer Institute** 800.422.6237 **National Coalition for Cancer Survivorship** 877.622.7937 **Cancer Care** 800.813.HOPE (4673) **American Pain Foundation** 888.615.7246 LIVESTRONG **Cancer Support Community** 

Survivorship A to Z

**Patient Advocate Foundation** 

cancer.gov canceradvocacy.org cancercare.org painfoundation.org livestrong.org cancersupportcommunity.org

cancer.org/survivorshipcenter

survivorshipatoz.org/cancer patientadvocate.org

cancer.org



### 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.



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.





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