

# **Your Cancer Resource Journal**

Learning that you have cancer can be one of the most upsetting moments in your life. All at once you may feel angry, frightened, sad and even physically ill. As your doctor explains your treatment options, you also may feel confused and overwhelmed.

These reactions are very normal. No matter how strong you are, cancer affects you physically and emotionally. Cancer also has an impact on your family and friends. No one can predict exactly what your cancer experience will be. We can, however, anticipate the kinds of information that you'll need to help you along during your care.

Your care team at Inova created this resource journal to help you and your loved ones get through this challenging time more easily. This journal will help keep track of your test results, medications, symptoms, appointments, treatments and resources. The journal includes information about the types of treatments that you may receive and what to expect during those treatments. The glossary will make you more comfortable with unfamiliar terms.

We strongly believe that keeping all of this information in one convenient place will make it easier for you and your loved ones to communicate with your care team members. **We** encourage you to download this journal, fill it out and print and take with you during visits to your physicians and hospital.

We also invite you to visit <a href="www.inova.org/cancer">www.inova.org/cancer</a> for information about specific types of cancer. You can learn about the opportunity to test the effectiveness of new cancer treatments through clinical trials. The web site also includes information about support services. Cancer services are available at each Inova location.

Throughout your cancer journey, our Life with Cancer program can help you meet the challenges of living with cancer by providing you and your loved one with education, information and support, free of charge, no matter where you live or receive treatment.

For more information on Life with Cancer call 703.698.2526 or visit www.lifewithcancer.org

#### Contents

My Journal	3
Medical History	3
Insurance Information	5
Care Team Members	6
Doctor Visits	7
Symptom Journal	8
Medication Journal	9
Treatment Journal	10
Test Results	11
Questions	12
Notes	13
My Physical Care	14
Understanding Cancer	14
Genetic Counseling	15
Medical Treatment	16
Surgical Treatment	20
Radiation Therapy	22
Interventional Radiology Therapy	28
Clinical Research Trials	
Coping with Side Effects of Cancer Treatment	
Supportive Care	
When Cancer Treatment Ends	
My Emotional Care	40
Take Charge of Your Cancer Experience	40
Education and Support Services	41
Cancer and Your Loved Ones	43
Complementary Therapies for Patients with Cancer	
My Financial Information	
Billing Information	
Glossary of Billing and Health Insurance Terms	
Resources	
Internet & Community Resources	
Glossary of Cancer Terms	
Important Phone Numbers	55

# **My Journal**

# **Medical History**

During your cancer experience it is likely that you will be asked about your medical history many times. Having all of this information in one place makes it easier to remember.

Primary care physician and phone number:			
Other physicians and phone numbers:			
Medical conditions, date of onset or diagnosis, and treatments:			
Family history of cancer (relation to you and type of cancer):			
Allergies (medication, environmental, food, latex, etc.):			

Hospitalizations (reason, date and hospital):		
Surgeries (reason, type of surgery, date, surgeon and hospital):		
Prescription medications (name, reason for taking and dose):		
Over-the-counter medications (name, reason for taking and dose):		
Vitamins, herbs and natural supplements (name, reason for taking and dose):		

# **Insurance Information**

When you visit your physician or hospital, you may frequently be asked about your insurance coverage or changes in your insurance coverage. Having all of this information in one place will make it easier to remember.

Primary insurance company	
Policy holder	-
Group number	
Plan number	-
Plan address	_
Phone number to verify coverage	
Co-pay amount	-
Primary care physician referral required?	_
If so, referral number and number of visits allowed	
Primary insurance company	
Policy holder	
Group number	
Plan number	-
Plan address	_
Phone number to verify coverage	_
Co-pay amount	-
Primary care physician referral required?	_
If so, referral number and number of visits allowed:	
Additional Insurance Information:	

## **Care Team Members**

An expert team dedicated to treating you as a whole person will coordinate your care during your cancer experience. But remembering who's who can be challenging. Writing down each person's name and contact information will make it easier for you and your loved ones to communicate with your care team members. Below is a list of common care team members.

	Name	Phone	E-mail
Primary Care Physician			
Medical Onc./Hematologis	t		
Surgical Oncologist			
Radiation Oncologist			
Radiologist			
Navigator			
Nurse			
Nurse			
Social Worker			
Dietitian			
Life with Cancer Oncology			

# **Doctor Visits**

(Print a new copy of this page for each visit)

Date/Time	Doctor
Purpose of this Visit	
r dipose of this visit	
Koy Questions	
Key Questions	
Key Decisions	
Ney Decisions	
Tests, Medications or Treatments Pre	escribed
Tests, Wedisalishs of Treatments Fre	Soliboa
Follow Up	
. oo.	

# **Symptom Journal**

Keeping track of your symptoms, such as pain, excessive fatigue or nausea, and what gave you relief, can help you deal with these symptoms should they recur. This information also may help your care team adjust your treatment.

Date	Symptom	What I Did	Did it Work?	How Did I Feel?

## **Medication Journal**

During your cancer experience you may need to take a variety of medicine. Keeping a medication diary helps you, your loved ones and your care team members keep track of this important part of your treatment. Try to use the same pharmacy for your prescriptions so that drug interactions can be avoided.

Pharmacy	name				
Pharmacy	location				
	phone number				
Start Date	Name	Dose	Reason	Notes (Is it effective?	How do I feel?

## **Treatment Journal**

During your cancer experience you may undergo several different types of treatment. A written record can help you follow your progress and mark important milestones. It also can help you better understand the bills that you receive.

Date	Treatment	Provider	Location

# **Test Results**

During your cancer experience you may need to undergo a variety of medical tests. Keeping a log can help you remember your results and make it easier to share them with your care team members. In addition to recording your test results here, you may want to request copies of test results for your records.

Date	Test	Results	Comments

# **Questions**

It is likely that you and your loved ones will have lots of questions during your cancer experience. Jotting them down as you think of them will help you remember to discuss them with your care team members.

Date	Question	Care Team Member	Answer

## **Notes**

Taking notes about information you hear or read during your cancer experience can help you and your loved ones stay informed. Please keep in mind that not everything related to cancer that you come across is medically sound. Some advice can be dangerous to your health. Always discuss this information with your care team members before acting on it.

Date	Information Source	Confirmation of Accuracy

# **My Physical Care**

# **Understanding Cancer**

A cancer diagnosis means you have one disease. But the term "cancer" actually applies to more than 100 different diseases that all begin the same way: normal cells transform to malignant cells, reproduce uncontrollably and destroy healthy tissue. Cancer cells reproduce despite a lack of space, the need to share nutrients with other cells and signals from the body to stop. Cancer cells often are shaped differently from healthy cells and do not function properly. Malignant tumors result when clusters of cancer cells form abnormal growths, which can spread to other parts of the body.

Cancer can start almost anywhere in the body:

- Carcinoma, the most common type, develops in tissue covering or lining organs of the body, such as breast, colon, lung, skin and uterus
- Leukemia begins in the immature blood cells in bone marrow
- Lymphoma begins in the lymph nodes and tissues of the immune system
- Myeloma grows in the plasma cells of bone marrow
- Sarcoma begins in the body's supporting tissues, such as bone, cartilage and muscle

Carcinomas and sarcomas tend to form solid tumors.

Your cancer may remain confined to the area where it began. It also can spread through the body in one of two different ways:

- Local invasion: cancer cells move directly into neighboring tissue
- Metastasis: cancer cells penetrate lymph and blood vessels, circulate through the bloodstream, and then invade normal tissues elsewhere in the body

Your original tumor is called the primary tumor. New tumors that form elsewhere in your body are called secondary or metastatic tumors. A cancer that metastasizes is named for the part of your body where it began. For example, cancer in your breast that spreads to your liver is still referred to as a breast cancer, which has metastasized to the liver.

Physicians have a wide range of radiation and drug therapies from which to choose. Combining two or more different therapies often proves extremely effective. For more information, visit <a href="www.inova.org/cancer">www.inova.org/cancer</a>. Our Web site includes a wealth of educational information about cancer, as well as news and updates about treatments.

## **Genetic Counseling**

People who learn they have cancer often want to know why. Here are some questions they may ask:

- Did my cancer "just happen" or is it inherited?
- Are my children and other family members at increased risk?
- Should I undergo genetic testing?
- Would the results of genetic counseling affect my cancer treatment?
- Am I at risk for developing other types of cancers?
- How do I encourage other family members to undergo cancer screening?

Our cancer genetic counselor can help provide some of the answers. These highly trained professionals specialize in cancer risk assessment. They help people understand the benefits, limitations and risks of genetic testing. They order tests, interpret the results and discuss ethical issues.

A genetic counseling appointment begins with a careful evaluation of your personal and family medical history. This information is very important in determining your cancer risk. Also, there are certain features in a family history that make it more likely that the cancer is inherited. Genetic testing is available for individuals and family members who are at increased risk for an inherited form of cancer.

Whether or not to have genetic testing is a very personal decision. You may want to consider genetic counseling if you answer yes to any of these questions:

- Did you or a blood relative receive a cancer diagnosis at a very early age?
- Do (did) many of your relatives on the same side of your family have cancer?
- Do (did) you or a blood relative have cancer more than once, such as breast and ovarian cancer or cancer in both breasts?
- Do (did) you or a blood relative have rare types of cancer? (ex. ovarian, pancreatic, sarcoma)

If you undergo genetic testing, which usually requires only a simple saliva sample, you will meet with the genetic counselor to discuss the results. Your counselor also will talk to you about the screening and management options available, a plan for sharing the results with your family and how to coordinate your care.

For more information about the Cancer Genetic Counseling program call **703.970.3209**.

#### **Medical Treatment**

**The Medical Oncology Care Team** Your medical oncology care team works together to meet your individual needs during the course of your treatment and follow-up. Each member is certified, licensed or registered in his or her specialty.

- Medical oncologist: physician specializing in treating cancer with drugs and chemicals (chemotherapy, hormone therapy)
- Oncology nurse: nurse specializing in caring for people with cancer and who also may administer chemotherapy and hormone therapy
- Social Workers/Oncology Counselors: provide emotional support, assistance with coping skills, which make it easier for you and your loved ones to focus on your treatment.

Please let your care team know if you have any questions or concerns.

#### What to Expect During Chemotherapy

Chemotherapy (chemo) uses drugs to destroy cells that divide and grow quickly. But these drugs often cannot tell the difference between cancerous cells and certain normal cells. Your oncologist will adjust your chemotherapy dose to limit the amount of damage to healthy cells.

Chemotherapy is most frequently delivered by intravenous (IV) injections, usually through a vein in your arm. Your doctor may recommend placing a central venous access catheter, also called a central line, so you do not need to have a needle stick at each session. Sometimes chemotherapy is combined with oral medication.

You may receive chemotherapy at a cancer center, in a doctor's office or at home. Depending on the type of chemotherapy you receive, each session may last from a few minutes to more than an hour. A full course of chemotherapy usually runs in two, three or four-week cycles over a four to six month period.

You may have a loved one or friend keep you company during your treatment, if that is what you want. If you prefer, bring your favorite music or relaxation tapes, or perhaps a recorded book.

Chemotherapy can cause unpleasant side effects, but many of the newer drugs are gentler to your body. Nonetheless, each person reacts differently to chemotherapy. Some side effects are associated with only specific drugs.

It is important that you tell your care team members about any side effects you experience. They can help minimize these side effects and make you as comfortable as possible by providing the following:

- medications and supportive care for diarrhea
- medications and supportive care for nausea and vomiting
- nutrition services
- pain management therapy
- medication to fight anemia
- information about blood donor services
- infection prevention
- information on wigs and other cosmetic items

# Frequently Asked Questions about Chemotherapy

**What exactly is chemotherapy?** Chemotherapy uses drugs to interfere with the way cancer cells divide and grow. Some chemotherapy drugs are taken by mouth. Most chemotherapy is delivered by injection into a vein (intravenous, or IV).

How long will my chemotherapy take? The answer depends on the type of chemotherapy you receive. Each session may last from a few minutes to more than an hour. A "round" or "cycle" of chemotherapy usually consists of multiple sessions scheduled at two, three or four-week intervals. You can expect a complete round of chemotherapy to take four to six months. Depending on how you respond to the treatment, you may need more than one round.

Can I drive myself to and from treatments? Each person reacts differently to chemotherapy. It's a good idea to have someone drive you during your first few sessions until you know how you feel.

Why does chemotherapy cause side effects? Chemotherapy drugs affect the frequently dividing cells in your body. However, the drugs can not differentiate between cells that are cancerous and those that are normal. Your digestive system, hair follicles, bone marrow, and ovaries (females) or testicles (males) contain fast growing cells. That is why they are prone to side effects.

What side effects will I have? Many of the newer chemotherapy drugs may be gentler to your body. Nonetheless, each person reacts differently to chemotherapy. Some side effects are associated with only specific drugs. Some effects of chemotherapy may be cumulative and irreversible. And in certain cases, side effects may not occur until months or years after your treatment ends.

The most common side effects you may experience are mouth sores (mucositis or stomatitis), diarrhea, nausea and vomiting, hair loss and fatigue. You also may be at increased risk for anemia, bleeding in the mouth or stool, and infection. Some side effects of chemotherapy, such as nausea, can be prevented or reduced with other medicines.

Men and women may experience temporary or permanent infertility, and women may experience early menopause. Although it is possible to become pregnant while undergoing chemotherapy, doctors advise against it because some cancer drugs may cause birth defects. Certain chemotherapy drugs are more likely to cause fertility problems. Doctors encourage people with cancer to use birth control throughout their treatment.

How will I manage these side effects? Your cancer care team will do everything possible to lessen any unpleasant side effects of chemotherapy. Your oncologist will prescribe medication to reduce the likelihood of nausea and vomiting and to treat any mouth sores or skin irritation you may develop. You also may receive medication to make you feel less tired. Your dietitian will help you keep up with your nutritional needs even when you don't feel like eating.

If I have side effects, will I feel them every day? No one can predict which side effects you will have and how severe they will be. In general, digestive side effects are most likely to occur within the first week of treatment. Excessive fatigue and risk of infection are most likely during the first two weeks. You may feel your best during the third week of each round.

How long do side effects last? Fortunately, after you finish your round of chemotherapy, your body begins repairing the damage to your normal cells. That is why your hair grows back after all chemotherapy is completed, although the color and texture may change. Infections clear up, and your energy returns. Most side effects fade quickly others may take months or longer to completely disappear. Your care team will discuss your specific side effects with you.

Can chemo cause permanent damage to my body? If the most appropriate chemotherapy drug for you is likely to harm a part of your body, your oncologist will monitor you closely during your treatment. That way, any changes in normal functioning can be found early and corrected.

Will I be able to work and take care of my family? Many people continue to keep a regular schedule while undergoing chemotherapy. Of course, there is no way to predict how you will feel during your course of treatment. Your oncologist will help you determine the level of activity that's best for you.

**How will I know the chemo is working?** Your medical oncologist will order tests that keep track of your progress. Learning that the chemotherapy is working can be powerful medicine!

Who will provide my care after I finish chemo? Your medical oncologist will follow you closely after your chemotherapy ends. Depending on your condition, you may be referred to a radiation oncologist and/or surgeon.

#### **Hormone Therapy**

In order to slow or stop the growth of certain cancers (such as prostate and breast cancer), synthetic hormones or other drugs may be given to block the body's natural hormones. Sometimes surgery is needed to remove the gland that makes a certain hormone.

Source: www.cancer.gov

### **Biological Therapy and Targeted Treatments**

Your immune system protects and defends your body against foreign invaders, such as bacteria or viruses. Your immune system may be able to differentiate between healthy cells and those that are cancerous. Biological therapy (immunotherapy) uses your body's own immune system to fight cancer.

Biological therapies may work in different ways:

- make cancer cells more susceptible to destruction by the immune system
- boost the killing power of immune system cells
- change the way cancer cells grow, so that they act more like healthy cells
- stop the process that changes a normal cell into a cancerous cell
- enhance your body's ability to repair or replace normal cells damaged or destroyed by other forms of cancer treatment
- prevent cancer cells from spreading to other parts of the body

Here are two examples of biological treatments:

**Cancer vaccines** are an experimental therapy that tries to train the immune system to recognize and attack cancer cells or make cancer cells stimulate an immune response

**Monoclonal antibodies** are laboratory-produced substances that locate and bind to certain receptors on cancer cells or other tissues to block growth of malignant cells

Targeted treatments cut off a tumor's blood supply or prevent defective genes from instructing cells to grow uncontrollably.

Side effects of biological therapy may include fever, chills, nausea, vomiting, loss of appetite and fatigue. Your care team will help you manage any side effects you may experience.

## **Surgical Treatment**

## **Surgical Treatment Overview**

Surgery is the oldest form of cancer treatment. It may be effective on its own or work in conjunction with chemotherapy and radiation. Cancer surgery can achieve different goals.

- **Diagnostic surgery** allows doctors to determine whether cells are cancerous and, if so, the type of cancer that you have (biopsy). Surgery also can help doctors learn how far your cancer has advanced (stage).
- Preventive surgery removes tissue, such as colon polyps, that contains the kinds of cells that often develop into a malignant tumor.
- **Curative surgery** removes cancerous tumors that are confined (localized) to a specific part of your body.
- Debulking surgery removes part of a cancerous tumor when removing the entire tumor
  may cause damage to organs. Your doctor may recommend that you undergo
  chemotherapy, radiation or both, after debulking surgery.
- Palliative surgery relieves discomfort and corrects problems caused by your cancer or cancer treatment.
- Supportive surgery helps you receive other cancer treatments more efficiently. One
  example is having a catheter, or narrow tube, inserted into a vein so you can receive
  chemotherapy and give blood samples without having to endure a needle stick each
  time.
- **Restorative surgery** helps bring back appearance or function after cancer surgery. Breast reconstruction following a mastectomy is one example.

Some surgeons specialize in the following cancer surgeries:

- Cryosurgery uses extremely cold temperatures to kill cancer cells. Doctors may apply liquid nitrogen directly or use a super-cooled instrument called a cryoprobe to reach the cancerous cells.
- Laser surgery uses beams of light energy to remove very small cancers, shrink tumors
  and activate drugs that destroy cancer cells. Laser surgery causes minimal damage to
  neighboring tissue.
- **Electrosurgery** uses electrical current to destroy cancer cells.
- **Microscopically controlled surgery** allows physicians to remove one layer of skin at a time until microscopic examination shows no remaining cancerous cells.
- Laparoscopic surgery is a less invasive form of surgery conducted through tiny incisions. It can be used for staging, resection or palliative surgery.

# Frequently Asked Questions for Patients Undergoing Cancer Surgery

#### Will surgery cure my cancer?

If your tumor is small and confined to a single area, your surgery may remove all the cancerous tissue. However, there is always a chance that some cancer cells may have spread to other parts of the body.

#### What are other reasons for having cancer surgery?

Your doctor may perform surgery to help stage your cancer, which determines how far your cancer has spread. Surgery also can remove as much cancerous tissue as possible (debulking) before you undergo chemotherapy or radiation to increase the effectiveness of those therapies. Or surgery may treat a problem such as blockage or pain that your tumor is causing.

An operation, such as breast reconstruction, can help restore your appearance or function after cancer surgery.

#### What are the risks of cancer surgery?

The risks are the same as those from other types of surgery: complications from anesthesia, damage to other organs, blood loss and reactions to medication.

### What problems may occur after my surgery?

You may experience infections, illnesses (such as pneumonia), blood loss or blood clots. A cancer care team member will help you minimize these risks and relieve any pain or discomfort.

#### Who will provide follow-up care after my surgery?

Your surgeon will monitor your care in the hospital and during office visits. If your surgeon believes that you can benefit from chemotherapy or radiation therapy, you will be referred to a medical oncologist or a radiation oncologist for further evaluation.

# **Radiation Therapy**

## Radiation Therapy Overview

Radiation therapy uses special high-energy beams to destroy cancer cells. Unlike cancer cells, however, normal cells usually repair themselves within a short period of time after your treatment ends.

#### **External Radiation**

External radiation therapy uses equipment outside your body to direct the high energy beams at your tumor. We carefully plan your treatment to target the area of cancer. You may receive your course of treatment five days a week for two to eight weeks. There are various ways to deliver radiation therapy. Two-dimensional simulation involves x-rays and measurements to line up treatment areas prior to beginning treatment. Three-dimensional conformal radiation uses CT scans to shape the treatment field. Intensity modulated radiation therapy (IMRT) goes a step further by using many beams of varying intensity to different parts of a tumor. Image-guided radiation therapy (IGRT) uses various imaging techniques to locate a tumor target prior to radiation therapy treatment. Your doctor will determine which way of delivering external beam radiation therapy is right for you.

Our radiation therapy is further enhanced by respiratory gating. In the past, when radiation beams were aimed at a tumor, body movement from breathing had to be accounted for and often resulted in a larger treatment area. With respiratory gating, radiation treatment is timed to an individual's breathing pattern, helping to target the tumor more precisely.

#### **Internal Radiation**

Internal radiation therapy delivers a high dose of radiation to a small area by placing the source of radiation, called an implant, within your body. Temporary implants are done with applicators designed specifically for these treatments and are removed after a short period of time. Gynecologic implants are examples of temporary implants. Permanent implants are done with radioactive seeds, remaining in the body forever, but they eventually stop giving off energy. Prostate seed implants are examples of permanent implants.

#### **Your Radiation Therapy Care Team**

Our specially-trained radiation therapy care team is certified, licensed or registered in his or her specialty. Please let your team know if you have any questions or concerns.

- Radiation oncologists are medical doctors who have extensive training in using high energy radiation to treat cancer.
- Radiation therapists have specialized training in radiation oncology to administer the actual treatment.

- Radiation oncology nurses provide educational support and assistance with exams and managing side effects.
- Dosimetrists use sophisticated computer programs to calculate the exact dose of radiation and to design the best shapes and angles for the treatment beams.
- Radiation physicists work with radiation oncologists to oversee the work of dosimetrists in treatment planning and are responsible for making sure the equipment delivers the right amount of radiation to the site.
- Social workers/oncology counselors provide emotional support and resources to help manage personal or family concerns that arise during treatment.
- Dietitians monitor weight and provide counseling to maintain or improve nutritional status during treatment.
- **Receptionists** greet patients, hand out information, assist with paperwork and appointments, and direct questions and phone calls to appropriate team members.

# Frequently Asked Questions Regarding Radiation Therapy

#### Will treatment make me radioactive?

External radiation will not make you radioactive. You do not have to worry about being close to others.

*Internal* radiation therapy, however, requires some special precautions to protect others. These include staying in a private hospital room, getting the care you need with limited contact with hospital staff, and restrictions on who can visit and how far visitors must stay from your bed. Your care team will carefully review these instructions with you.

## Can I continue to work while undergoing radiation therapy?

Many people continue to work as usual while undergoing external radiation therapy. Your care team can help you talk to your employer if you need to make adjustments to your regular schedule.

### Will I lose my hair?

If you are receiving radiation therapy to your head, you may experience temporary or permanent hair loss. To be prepared, you may want to purchase a wig or other head coverings before beginning your treatment. You will not lose the hair on your head if other parts of the body are being treated.

#### What about sexual relations?

Like chemotherapy, radiation therapy may cause side effects such as fatigue, nausea and vomiting, diarrhea, and other symptoms that can decrease feelings of sexuality. Causes are

often both physical and psychological. An individual's sexual response can be affected in many ways. Not all patients experience the same side effects or have the same concerns. The most common sexual problems for people who have cancer are loss of desire for sexual activity in both men and women, problems achieving and maintaining an erection in men, and pain with intercourse in women. Your care team has suggestions to help you manage and understand these changes.

Although you may have sexual relations as usual during radiation therapy, you should use birth control throughout your treatment. Ultimately, sexuality is defined by each patient and his/her partner according to sex, age, personal attitudes, and religious and cultural values.

#### Can I exercise?

Exercise is good for your body and your sense of well-being. You may exercise throughout your course of treatment as much as your energy level allows.

#### Can I drive myself to and from treatment?

Most patients drive themselves to and from treatment without difficulty. You may want to have someone drive you the first few times, just to see how you feel.

### Which doctor is in charge of my care?

Your radiation oncologist will evaluate and treat symptoms related to radiation therapy during your course of treatment. Your referring physician, primary care physician and medical oncologist will maintain responsibility for your medical care.

#### Will there be any side effects?

That depends upon the part of the body that is being treated. Side effects include fatigue, nausea, diarrhea and skin changes. Any side effects you do experience usually start about two weeks after treatment begins and peak around, or after, the fourth week. Side effects usually go away in the first few weeks after treatment ends. You can find information about managing side effects in this journal. Your care team will provide information and answer questions.

#### How will I know that the radiation is working?

After your radiation therapy is complete, you will have a follow up visit with your radiation oncologist. You will undergo any necessary additional tests after your body has had sufficient time to heal.

#### Who provides care after radiation therapy?

Your follow-up care depends on the kind of cancer you have and additional treatments you may need. Most patients see their radiation oncologist for regular follow-up visits. Some patients are referred to their primary care physician, a surgeon or a medical oncologist. Medical oncologists, radiation oncologists and surgeons work together as a team to ensure that you get the cancer therapy that is right for you.

# What to Expect During External Radiation Therapy

Following are the steps and appointments during the course of External Radiation Therapy.

- 1. Physician Consultation
- 2. Simulation and Treatment Planning
- 3. Verification Simulation
- 4. Daily Treatments
- 5. On Treatment Visits
- 6. Follow-up Visits

**Physician Consultation:** The purpose of this visit is to meet with the radiation oncologist and discuss the role of radiation therapy in your treatment, and the kind of radiation therapy to be used. The doctor will discuss the potential benefits and risks of radiation therapy and answer any questions you may have. You will also be seen by a radiation oncology nurse who will educate and guide you through the entire radiation oncology treatment process.

**Simulation and Treatment Planning:** Simulation is the planning session during which your care team decides exactly how to administer radiation therapy. Simulation takes approximately an hour. You may eat and drink as usual before your simulation unless you were told otherwise.

During simulation you will lie on a table. Your care team will determine the best treatment position for your body. Immobilization devices such as headrests, molds, casts or other devices may be used to help you remain in the same position during the entire treatment. Depending on the area to be treated, it may be necessary to insert a catheter, or tube into your bladder, rectum or vagina to identify these areas on the scan.

Once the treatment position is determined and scanning is completed, tiny tattoos, permanent black marks (about the size of the head of a pin) might be placed on your skin. These tattoos will be used by radiation therapists to place you in the exact position for each treatment.

After simulation, the information is forwarded to medical dosimetrist and medical physicist. Special treatment planning computers will be used by your radiation oncologist, dosimetrist and physicist to plan your treatment. The planning process can be very complex and time consuming and may take up to two weeks. We understand your desire to start treatments soon, and we will make every effort to finish the plan as quickly as possible but with great care to ensure safety and accuracy.

**Verification Simulation**: This is the first appointment the treatment machine (Linear Accelerator) prior to the start of the treatment. This procedure ensures the accuracy of positioning treatment set-up. A set of films will be taken with you on the treatment table. These films will be checked to ensure accuracy. The actual treatment will usually start the following day.

**Daily Treatments:** Radiation treatment is usually given five days a week for two to eight weeks. Each treatment generally takes less than 20 minutes. Much of the time is spent in positioning the patient to ensure accuracy for the treatment and the remaining time for actual treatment delivery.

To deliver treatment, the therapists will go outside the treatment room and commands the linear accelerator from a Control area. The therapist will closely monitor via a camera and intercom system. Treatment delivery may be given from one to many directions and each radiation beam may be on for anywhere from ten seconds to several minutes.

Verification films will be taken daily or every five treatments. Physician will review these films to ensure that treatments are delivered accurately. If needed, adjustments will be made to maintain the accuracy of treatments. These verification films are generally not used to evaluate the response of the disease but are strictly used to ensure treatment accuracy.

You should plan on about 30-60 minutes in our department each day for your daily treatments.

**On Treatment Visits:** At least once a week you will be seen by the nurse and the radiation oncologist. This is to follow your progress and to evaluate and manage any side effects. You can always talk to your nurse or radiation oncologist during your treatment if you have any concerns. They are available every day.

**Follow-Up Visits:** After your radiation therapy course is completed, follow-up appointment will be scheduled about two weeks later. This is to monitor your health status and to evaluate any residual side effects of your treatment. With time, the frequency of follow-up visit will decrease. However, you are encouraged to contact us any time if you have any questions or concerns.

#### What to Expect During Internal Radiation Therapy

Internal radiation therapy, also known as brachytherapy, places a radioactive material directly into, or as close as possible to, the cancer. Internal radiation therapy allows your doctor to give a dose of radiation to a smaller area and in a shorter time than is possible with external radiation treatment.

Most brachytherapy is put in place through a catheter, which is a small, stretchy tube. Sometimes, it is put in place through a larger device called an applicator. When you decide to have brachytherapy, your doctor will place the catheter or applicator into the part of your body that will be treated.

#### **Meeting with your Care Team**

You will have a meeting with your doctor or nurse before you begin internal radiation therapy. At this time, you will have a physical exam, talk about your medical history, and maybe have

imaging tests. Your doctor will discuss the type of internal radiation therapy that is best for you, its benefits and side effects, and ways you can care for yourself during and after treatment. You can then choose whether to have internal radiation therapy.

#### **How is Brachytherapy Administered?**

Most brachytherapy is put in place through a catheter, which is a small, stretchy tube. Sometimes, it is put in place through a larger device called an applicator. When you decide to have brachytherapy, your doctor will place the catheter or applicator into the part of your body that will be treated

You will most likely be in the hospital when your catheter or applicator is put in place. Here is what to expect:

- You will either be put to sleep or the area where the catheter or applicator goes will be numbed. This will help prevent pain when it is put in.
- Your doctor will place the catheter or applicator in your body.
- If you are awake, you may be asked to lie very still while the catheter or applicator is put in place. If you feel any discomfort, tell your doctor or nurse so he or she can give you medicine to help manage the pain.

#### **After Treatment**

Once your treatment plan is complete, radiation will be placed inside the catheter or applicator. The radiation source may be kept in place for a few minutes, many days, or the rest of your life. How long the radiation is in place depends on which type of brachytherapy you get, your type of cancer, where the cancer is in your body, your health, and other cancer treatments you have had.

Source: www.cancer.gov

## **Interventional Radiology Therapy**

If your cancer is inoperable, it means it cannot be removed by surgery. However, you may benefit from minimally invasive treatments that deliver cancer-fighting therapy directly to the tumor. To administer these treatments, interventional radiologists (a board certified physician with special training in medical procedures that involves radiology and imaging techniques) use moving X-ray pictures to guide them as they insert tiny devices through small nicks in the skin.

Here are some examples of cancer-fighting therapies that involve interventional radiology:

- Radiofrequency ablation (RFA) uses heat to destroy a tumor while posing little risk to neighboring normal tissue
- Cryotherapy (cryoablation or cryosurgery) uses extreme cold to destroy a tumor.
   Cryotherapy often is used to treat prostate cancer and may be an appropriate alternative to prostate surgery for men who are older, in poor health, or who have recurrent prostate cancer.
- Chemoembolization delivers cancer-fighting drugs through a tiny tube directly into a tumor
- Radioembolization delivers radiation directly to the tumor through millions of microscopic radioactive spheres, called SIR-Spheres® or TheraSpheres®, where they destroy the tumor by depositing millions of tiny radioactive emitters around the tumor.

Many interventional radiology procedures can treat cancer on an outpatient basis or during a short hospital stay. These procedures may have fewer side effects and complications and lead to quicker recoveries than other types of therapies.

### **Clinical Research Trials**

When you receive care through Inova, you may have access to promising new investigational drugs and therapies (clinical trials) that often are not available elsewhere in the area.

Our centers are affiliated with the following study groups of the National Cancer Institute, a division of the National Institutes of Health:

- American College of Surgeons Oncology Group
- Radiation Therapy Oncology Group
- Cancer and Leukemia Group B
- Eastern Cooperative Oncology Group
- Gynecological Oncology Group
- National Cancer Institute of Canada Clinical Trials Group
- National Surgical Adjuvant Breast and Bowel Project
- North Central Cancer Treatment Group
- Pediatric Oncology Group
- Southwest Oncology Group

We also participate in clinical trials sponsored by pharmaceutical companies, and companies that manufacture medical and radiological devices.

Your oncologist will tell you about any trials for which you may qualify. For more information, please call the Inova Research Center at **703.776.2580**.

A current listing of open adult and pediatric clinical trials is provided on the Inova web site at <a href="https://www.inova.org/cancer">www.inova.org/cancer</a>

For more information about clinical trials, visit the National Cancer Institute's Web site at <a href="https://www.cancer.gov/clinical\_trials">www.cancer.gov/clinical\_trials</a> or call **1.800.422.6237**.

## **Coping with Side Effects of Cancer Treatment**

#### Hair Loss

If you undergo certain treatments for cancer, you may lose your hair. Many people with cancer say that dealing with hair loss is one of the most difficult parts of their entire cancer experience. Hair loss not only affects your self-esteem and quality of life, it also makes public what you may not want to share.

Your hair may begin to fall out one to three weeks after you start chemotherapy or radiation treatment. Some people prefer to take control of the hair loss experience by shaving their heads or purchasing a wig.

It is important to understand that if you undergo chemotherapy, you may lose hair all over your body. This includes eyebrows, eyelashes, facial hair and pubic hair, not merely the hair on your scalp. Your hair should start to grow back soon after your last treatment. It may take up to a year to completely re-grow, may have a different color or texture, but these changes usually are only temporary. If you undergo radiation only, any hair loss you have will be confined to the treated areas. However, the loss may be permanent.

If you plan on wearing a wig or toupee, it's a good idea to make your purchase and have it styled in advance. Wig salons also sell caps, scarves and turbans that can add to your comfort. You should obtain a prescription from your doctor for insurance purposes, as some health insurance plans cover the cost of wigs for people undergoing cancer treatment. Wigs also may be tax-deductible. Save your receipts. If you cannot afford a wig, speak to your social worker who can provide resources for financial aid.

For women, the *Look Good...Feel Better* program, a joint venture of the American Cancer Society, the Cosmetics, Toiletry and Fragrance Association Foundation, and the National Cosmetology Association, can make referrals to a volunteer cosmetologist who will offer make up and styling tips to enhance your appearance and boost your self-esteem. For more information on this program, please call **703.938.5550** 

# **Fatigue**

Fatigue is an extremely common symptom during the cancer experience. You may feel exhausted, your arms and legs may feel heavy, and you may lose interest in doing everyday activities. Fatigue also can make it difficult for you to walk even short distances, enjoy family and friends, feel productive and enjoy intimacy with your partner.

Fatigue may result from your treatment. Chemotherapy can lower your red blood cell count (anemia) and deprive your cells of adequate oxygen. Your doctor may prescribe medication that helps maintain normal red blood cell levels. Or you may benefit from a blood transfusion. Even if chemotherapy does not cause anemia, you may still experience fatigue from the cancer itself.

Cancer itself or treatment side effects, such as pain and vomiting, also can increase your fatigue. Fatigue also may be the result of medications used to treat other side effects. Many of the medications used to treat nausea also may make you sleepy. Talk to your care team, as they may be able to provide an equally effective medication that does not have the same sedative property.

During radiation therapy, you may feel fatigue as your body works extra hard to destroy cancer cells. Radiation-related fatigue often is worse at the end of the week and toward the end of the full course of treatment.

Fatigue gradually diminishes after your treatment ends. But it is important to talk to your doctor about fatigue during your treatment. Here are some important ways to manage fatigue:

- save your energy for important tasks
- say "yes" when family, friends and neighbors offer help
- allow people to provide meals that you can prepare easily
- appoint a "task master" to allocate jobs to others
- use your Inova cancer patient journal to save mental energy
- call your doctor or nurse if you experience unusual fatigue

Stress and strain also can cause fatigue. Laughter, music and sharing feelings can help ease the burden.

## Susceptibility to Infection

People with cancer often are susceptible to infection. That is because the disease itself and many cancer treatments weaken the immune system and affect the production of blood cells. Chemotherapy can destroy some of your bone marrow, where infection-fighting white blood cells are produced. Low white blood cell count is known as leukopenia or neutropenia. Radiation rarely causes leukopenia. However, this side effect is more likely to occur if you are also undergoing chemotherapy.

Infection can begin anywhere in your body. The most common sites are the mouth, skin, lungs, urinary tract, rectum and reproductive organs. Here are some ways to reduce the risk of infection:

- Wash hands often, especially before and after using the toilet and before eating
- Stay away from people who have contagious diseases, including cold and flu
- Avoid crowds
- Stay away from children with recent immunizations, such as vaccines for polio, measles, mumps and rubella (German measles)
- Clean your rectal area gently, but thoroughly, after each bowel movement. Tell your doctor
  or nurse if the area becomes irritated or if you have hemorrhoids. Check with your doctor or
  nurse before using enemas or suppositories.

- Don't cut or tear the cuticles of your nails
- Try not to cut or nick yourself
- Use an electric shaver to prevent breaks or cuts in your skin
- Use an extra soft toothbrush that won't hurt your gums, and check with your doctor or nurse regarding whether you should floss
- Don't squeeze or scratch pimples
- Take a warm bath, shower, or sponge bath every day. Gently pat your skin dry.
- Use lotion or oil to soften and heal dry or cracked skin
- Clean cuts and scrapes right away with warm water, soap and antiseptic
- Wear protective gloves when gardening or cleaning up after animals and others
- Do not get any immunizations without first checking with your doctor or nurse

Even if you are very careful, you may not be able to fight off infections when your white blood cell count is low. Check your body regularly for signs that you might have an infection. Pay special attention to your eyes, nose, mouth, and genital and rectal areas. Symptoms of infection include:

- fever of 100.5°F or greater
- chills
- sweating
- loose bowels or diarrhea (this can be a side effect of chemotherapy)
- burning when you urinate
- severe cough or sore throat
- unusual vaginal discharge or itching
- redness, swelling, or tenderness, especially around a wound, sore, pimple, IV catheter site or vascular access device
- abdominal pain

Report any signs of infection to your doctor or nurse immediately. If you have a fever, *don't* use aspirin, acetaminophen (Tylenol), ibuprofen (Advil), or any other medicine to lower your temperature without first checking with your doctor or nurse.

# Constipation

Certain medications that you take during your cancer treatment, such as for pain or anemia, may cause constipation. Once your treatment ends, your bowels should gradually return to normal. Meanwhile, here are some suggestions that may provide relief:

- drink 8 to 10 glasses of liquids each day
- drink hot liquids to stimulate bowel activity
- add 1 to 2 tablespoons of bran to your food each day
- eat high fiber foods, such as dates, figs, oatmeal and raisins
- remain as active as possible
- set aside at least 15 minutes a day to sit quietly on the toilet

Your dietitian will help you plan meals that encourage normal bowel movements. Also, your physician may prescribe laxatives or stool softeners. Do not use suppositories, enemas or any over-the-counter products without your doctor's permission.

# Nausea or Vomiting

You may experience nausea or vomiting after your chemotherapy or radiation therapy treatment. Help manage these side effects by following these suggestions:

- replace your usual three meals a day with six smaller meals
- eat dry foods, such as toast or crackers
- avoid foods that are highly sugary, seasoned, spicy or have strong odors
- eat foods that are low in fat
- drink cool beverages
- drink beverages 30 to 60 minutes before eating instead of with meals
- rest after eating, but do not lie flat for several hours
- eat foods at room temperature
- ask your nutritionist to assist you in meal planning

Some people can make nausea go away by distracting themselves, breathing deeply and wearing loose fitting clothes. If nausea and vomiting become troublesome, please tell your doctor or nurse. Let them know if the prescribed medication does not provide the relief you need.

### Diarrhea

Certain cancer treatments, such as radiation to the abdomen or pelvis, or chemotherapy, can cause diarrhea. As unpleasant as this may be, it is temporary.

Here are some suggestions that may help:

- avoid milk products, except vogurt
- drink plenty of fluids
- eat potassium-rich foods, such as bananas, fish, meat and potatoes
- avoid high-fat, greasy, spicy and overly sweet foods
- avoid extremely hot foods
- avoid foods that cause gas, such as beer, beans, broccoli and cabbage
- don't chew gum
- ask your nutritionist to help you plan low roughage meals

If you develop frequent bowel movements, you may use Imodium AD, which is available without a prescription. Take a single dose of Imodium AD after each loose bowel movement. Do not use more than 10 times a day without first checking with your doctor or nurse. If diarrhea persists, your doctor can prescribe other medications.

## **Supportive Care**

## Pain Management

Maybe you assume that because you have cancer you will feel pain. Not every cancer causes pain. Some rarely cause any pain at all. Pain may arise if your tumor enters sensitive parts of your body, such as bone or nerves. Chemotherapy, radiation and surgery also may cause pain.

At Inova, our pain management team recognizes that pain can impact your quality of life. We understand the importance of assessing the nature of your pain, and we are committed to relieving it. We will ask you to rate your pain on a scale from 1 (no pain) to 10 (worst possible pain) or choose a face from a printed sheet that best describes the way you feel. We also will ask you to describe the kind of pain you feel and where it is located. Then we will offer the most effective treatment for your specific pain-relief needs.

Each person responds to pain differently. Your cultural practices may influence your pain experience. You and your loved ones may have misconceptions about pain management. Also, you may not realize there are many different ways in which to help manage your pain. These include medications that keep you from feeling pain, medications that reduce swelling and soreness, and heat or cold, relaxation and physical therapy.

Here are some common concerns about pain medicine:

I will become "hooked" or addicted. Studies show that this is very rare. Pain medicine will help you sleep and eat better and recover faster. As you begin to feel better, you will need less medication.

The medicine will stop working if I take too much. The medicine will not stop working, but your body will get used to it. This is called tolerance. When tolerance occurs, we can change the amount or type of medicine.

I can take medicine only when I have severe pain. Pain is much easier to control when it is mild than when it is severe. It is important that you not wait until your pain increases to take your medicine.

I am not being a good patient if I complain too much. You have every right to ask for and receive the pain relief you need. Controlling your pain is an important part of your care.

I do not want to lose control. Pain medicines can make you feel confused, dizzy or lightheaded. Report these feelings to your doctor or nurse immediately. Changing the amount or type of medicine often can help.

It is important for you to become an active participant in your pain management. Please remember that pain relief is readily available. You are entitled to it at any time. You need to tell us if the relief you feel is not what you expected.

### **Nutrition Services**

There may be times during your cancer treatment when it becomes difficult or unpleasant for you to eat. Your cancer care team members understand and want you to know this is a temporary situation.

Eating healthful foods is an important part of your therapy. A good diet helps you maintain your strength and rebuild body tissues affected by your treatment. It also can help you tolerate side effects better. And you may even be able to receive higher doses of some treatments that fight cancer better.

Our nutrition services for people with cancer help you maintain the healthiest diet possible during your treatment. Registered dietitians will evaluate your food intake, help you make adjustments to meet your individual needs, and assist you in managing any nutrition-related problems that may arise. Dietitians will also evaluate any vitamin, mineral or herbal supplements you already use or may be considering.

Your physician, nurse, radiation therapist or social worker will refer you to our nutrition services program at no cost. You or your family may request a consultation with the dietitian in regarding many conditions including:

- sore mouth or throat
- swallowing difficulty
- dry mouth
- taste change
- loss of appetite
- nausea and vomiting

- constipation
- diarrhea
- problems associated with feeding tubes
- food supplements
- weight management

#### Rehabilitation Services

Cancer and its treatment may limit function or mobility, decrease range of motion or cause pain. As you go through your cancer experience, Inova will continually assess your rehabilitation needs and offer individualized programs to keep you as independent as possible.

- Physical therapy restores loss of function through exercise, reconditioning, and assessing your need for bracing or other equipment.
- Occupational therapy educates and assists in improving endurance, self-care skills and your ability to perform activities of daily living.
- **Speech therapy** improves speech and swallowing difficulties.

Lymphedema therapy -patients with cancer who undergo certain lymph node dissection may be recommended to undergo lymphedema therapy. Also known as complete decongestive therapy, this comprehensive program minimizes any pain and swelling that follows a disruption to the normal flow of lymphatic fluid. Lymphedema therapy consists of intensive in-clinic drainage, exercises and training in self-care to optimize your condition.

## Home and Long-term Care

Inova's services reach beyond hospitals to include nursing homes, assisted living centers and home care. Inova provides long or short-term continuous care at nursing homes and assisted living centers. However, sometimes the best place to recuperate is at home. Inova VNA Home Health's nurses, home health aides, social workers and therapists provide home care for anyone needing it, including the sick, injured, disabled and terminally ill, and those who need care after being discharged from the hospital.

#### Palliative Care

Palliation is treatment for a symptom of cancer, such as pain. It is not a treatment for the cancer itself. Palliative care helps you retain reasonable function and quality of life by relieving pain, other symptoms and concerns. It is a way of managing your physical, social, psychological and spiritual needs. Your care team is sensitive to your need for palliative care, and if needed, can refer you to a palliative care physician.

### **Blood Donor Services**

Certain cancer treatments may damage your bone marrow. Bone marrow is the tissue that produces red blood cells (RBCs), white blood cells (WBCs) and platelets. Red blood cells carry oxygen throughout your body. White blood cells help you fight infection, platelets help your blood to clot.

Damage to bone marrow is known as bone marrow suppression, or myelosuppression. Your doctor will check your blood counts frequently. Until your bone marrow cells recover, you may have abnormally low numbers of red blood cells, white blood cells and platelets. In some cases your doctor may recommend that you receive a transfusion of blood products.

Cancer patients who will undergo surgery may be eligible to donate blood in advance for their own use. This process is called autologous donation. Your surgeon and primary care physician will determine if you are a suitable candidate for autologous donation.

Inova Blood Donor Services collects blood from voluntary donors to meet the needs of patients like you. There are four donor centers as well as community blood drives. More donors are always needed. Your loved ones can support these efforts by donating blood on a regular basis. The entire donation process, from registration to refreshments, takes less than one hour. For information, please call Inova Blood Donor services at **1.866.BLOODSAVES** (866.256.6372), or visit <a href="https://www.inova.org/donateblood">www.inova.org/donateblood</a>

#### **When Cancer Treatment Ends**

You should retain your journal that summarizes the medicines you have taken and the treatments you have received. This information will help your healthcare team provide you with better follow-up care. After investing so much time and energy into reaching this point, it may feel strange to resume your everyday routine. So while you begin to feel better physically, you may find this an emotionally difficult time.

In addition to the many other programs and services <u>Life with Cancer</u> offers people experiencing cancer treatment, the organization also offers monthly Survivorship Seminars.

These education and support groups are for people facing the challenges of surviving cancer. Life with Cancer also provides oncology counseling and complementary therapies, such as expressive arts, mindful meditation, and yoga for mind-body health.

Any side effects you experienced during your therapy should diminish over the next few weeks and months following your last treatment. Please continue following the supportive care suggestions as needed.

Almost everyone who has had cancer is afraid that it will come back, or recur. Many people mistakenly believe that a cancer recurrence means a cure is not possible. Medical advances allow some recurrent cancers to be treated successfully. Even if a cure is not possible, there are many ways to successfully manage existing cancers.

Good follow-up care allows early detection of any possible recurrence. During a series of follow-up visits, your oncologist or surgeon will examine you and order any appropriate tests. You will learn what symptoms to be aware of and report to your doctor. Please be sure to keep all of your appointments.

Often, recurrences are identified by patients between scheduled doctor visits. If your doctor suspects that you cancer has recurred, you may need to undergo additional diagnostic tests such as laboratory tests, imaging studies and/or biopsies.

Your doctor may refer you to another oncologist or surgeon for further evaluations. Be sure to check with your health insurance plan to see if you need a referral from your primary care doctor.

### What Is Follow-up Care?

Follow-up care means seeing a doctor for regular medical checkups. Your follow-up care depends on the type of cancer and type of treatment you had, along with your overall health. It is usually different for each person who has been treated for cancer. In general, survivors usually return to the doctor every 3 to 4 months during the first 2 to 3 years after treatment, and once or twice a year after that. At these visits, your doctor will look for side effects from

treatment and check to see if your cancer has returned (recurred) or spread (metastasized) to another part of your body.

#### **Survivor's Wellness Plan**

After cancer treatment, many survivors want to find ways to reduce the chances of their cancer coming back. Some worry that the way they eat, the stress in their lives, or their exposure to chemicals may put them at risk. Cancer survivors find that this is a time when they take a good look at how they take care of themselves. This is an important start to living a healthy life.

When you meet with your doctor about follow-up care, you should ask about developing a wellness plan that includes ways you can take care of your physical, emotional, social, and spiritual needs. If you find that it's hard to talk with your doctor about these issues, it may be helpful to know that the more you do it, the easier it becomes. And your doctor may suggest other members of the health care team for you to talk with, such as a social worker, clergy member, nurse or members of the Life with Cancer staff.

#### A Few Suggested Changes You May Want to Make

**Quit smoking**. Research shows that smoking can increase the chances of getting cancer at the same site or another site.

Cut down on how much alcohol you drink. Research shows that drinking alcohol increases your chances of getting certain types of cancers.

**Eat well.** Healthy food choices and physical activity may help reduce the risk of cancer or recurrence. Talk with your doctor or a nutritionist to find out about any special dietary needs that you may have. The American Cancer Society and the American Institute for Cancer Research have developed similar diet and fitness guidelines that may help reduce the risk of cancer:

Eat a plant-based diet and have at least 5-9 servings of fruit and vegetables daily. Try to include beans in your diet (but avoid if diarrhea is present) and eat whole grains (such as cereals, breads, and pasta) several times daily. Choose foods low in fat and low in salt. Get to and stay at a healthy weight.

**Exercise and stay active.** Several recent reports suggest that staying active after cancer can help lower the risk of recurrence and can lead to longer survival. Moderate exercise (walking, biking, swimming) for about 30 minutes every - or almost every - day can help reduce anxiety and depression and improve mood and boost self-esteem. It is important to start an exercise program slowly and increase activity over time, working with your doctor or a specialist (such as a physical therapist) if needed. If you need to stay in bed during your recovery, even small activities like stretching or moving your arms or legs can help you stay flexible, relieve muscle tension, and help you feel better. Some people may need to take special care in exercising. Talk with your doctor before you begin any exercise program.

#### **Getting the Most from Your Follow-up Visits**

Here are some ideas that helped others with their follow-up care:

- Ask someone to come with you to your doctor visits. A friend or family member can help you think about and understand what was said. He or she also may think of new questions to ask.
- Make a list of questions ahead of time and bring it with you.
- Take notes or ask if you can tape-record the answers.
- Ask your most important questions first, in case the doctor runs out of time.
- Don't be afraid to ask for more time when you make your next appointment. Or ask the doctor to suggest a time when you could call and get answers to your guestions.
- Ask to talk with the doctor or nurse in a private room with the door closed.
- Express yourself clearly.
- Describe your problem or concern briefly.
- Tell the doctor how your problem or concern makes you feel.
- Ask for what you want or need, for example, "I am tired most of the time each day. I've tried napping, but it doesn't help. My fatigue gets in the way of my daily life. What can be done to help me with this problem?"
- Tell your doctor if you need more information.
- Ask for booklets or other materials to read at home.
- Ask the doctor to explain what he or she said in terms you understand.
- Repeat back in your own words what you think the doctor meant.
- Ask your doctor or pharmacist about the best way to take your medicine and about possible side effects.
- Keep your own set of records about any follow-up care you have.

Source: www.cancer.gov and type in "Life After Treatment" in the search box

# **My Emotional Care**

## **Take Charge of Your Cancer Experience**

Each person manages their cancer experience in a unique way. Some people are comfortable following their doctor's advice. Others ask questions, do research, even get second and third opinions, before proceeding on to treatment. Research shows that people who take part in decisions about their health care are more likely to have better outcomes.

Many patients often find it difficult to speak up and assert themselves, but always keep in mind that no matter how crowded your doctor's waiting room may be, your doctor owes you undivided attention when it is your turn to be seen. Don't let your doctor rush you. And make sure you get all the information you need before you walk out the door.

You may want to take this journal with you to your appointments so that all medical information is in one place. Come prepared with a written list of questions to help you remember what you need to ask. Don't forget to check off each question. Then write down what your doctor tells you. Better yet, ask permission to tape the visit.

A helpful reminder to help you take charge of your cancer experience is to

#### SPEAK UP:

**S**elect health care providers that meet quality and safety standards

Pay attention to the treatment and medication you are receiving

Educate yourself regarding your diagnosis, tests and treatment plan

Ask a trusted friend or family member to be your advocate and attend appointments with you

Know what medications you take and why you take them

**U**nderstand what is happening to you and ask about anything unclear

Participate in all decisions about your treatment

## **Education and Support Services**

Inova provides education and support for you and your loved ones through Life with Cancer

#### What is Life with Cancer?

- Life with Cancer is one of the most far-reaching educational and support programs of its kind in the nation, providing information, education and support to patients and family members before, during and after treatment.
- Life with Cancer is part of Inova Health System, and works closely with physicians and other health care professionals to provide the most comprehensive services to cancer patients.
- Life with Cancer provides services at no cost to people affected by cancer, regardless of who their physician is, where they live, or where they receive treatment.

#### Life with Cancer offers:

- Information and referrals
- One-on-one education consults with oncology-certified nurses
- Short-term counseling with licensed oncology counselors
- Classes and seminars about specific cancer types
- Fitness classes, including: chair-based exercise and traditional exercise
- Expressive arts classes, including: writing, art, music and movement
- Complementary approaches, including: yoga, meditation, relaxation, imagery, Reiki, knitting circle and spirituality quest
- Classes and groups including chemo 101, managing treatment side effects, understanding lab values, 'Look Good...Feel Better', lymphedema group, stem cell group, nutrition classes and cooking demonstrations
- Support groups for specific cancers, including: brain, breast, colorectal, gynecological cancers, head and neck, leukemia, lung, lymphoma, melanoma, multiple myeloma and prostate.
- Support groups for young adults, women, men, couples and caregivers
- Programs and counseling for children and teens who have cancer or have a loved one with cancer
- Classes and groups in Spanish include Latinas Unidas, Sanando Juntos, Luzca Bien...
   Siéntase Mejor and Taller de Cáncer: Vive, Transforma y Aprende de tu Experiencia de Cáncer.
- For a complete listing, or to register for Life with Cancer classes, groups or services, go to <a href="http://www.lifewithcancer.org">http://www.lifewithcancer.org</a> and click on the Monthly Calendar page or call 703.698.2526

#### **Social Workers/Oncology Counselors**

Social workers understand the wide range of feelings and issues that a cancer diagnosis can evoke. They provide emotional support, assistance with coping skills, and referrals to resources, such as transportation providers, which make it easier for you and your loved ones to focus on your treatment.

Please discuss any financial concerns you or your loved ones may have in conjunction with your cancer treatment. Your social worker can refer you to pharmaceutical and patient assistance programs that relieve many of these burdens.

Because social workers may see you on a daily basis over a period of several weeks, they are in a unique position to detect even subtle changes that may suggest a need for counseling. Social workers work closely with dietitians to ensure that you maintain proper nutrition throughout the course of your treatment. Also, they respond to concerns that other members of your care team may raise.

### **Patient Care Navigators**

Our navigators are available to ensure that patients with certain cancer diagnosis receive care and have access to the resources they need in a timely and efficient manner. Our navigators provide clinical education and printed materials to help patients further understand their diagnosis; referrals to appropriate social and supportive services in both the hospital and community; communication with physicians and other care providers; emotional support; and referrals to one-on-one counseling services, clinical trials access, as well as services and resources for the patient's family members and caregivers.

#### **Pastoral Care**

Chaplains can help caregivers, patients and their families with the bioethical, cultural and religious issues that may arise during the course of the cancer experience. You or your loved ones may request a chaplain through any member of your care team.

#### Cancer and Your Loved Ones

Cancer affects everyone around you. Friends and family want to help you through your journey. Yet at times they may feel helpless and confused.

Your loved ones may benefit from talking to others who are going through a similar experience. The Caregivers Meeting is a drop-in group for friends and family members of people with cancer. For more information and to confirm meeting location and time, please call Life with Cancer at **703.698.2526**.

Here are some ways that family and friends can help:

- · accompany you on medical appointments
- grocery shopping
- housekeeping
- prepare meals
- take over carpool duties.

## **Complementary Therapies for Patients with Cancer**

Complementary therapies are designed to enhance your quality of life as you go through the cancer experience. Complementary therapies do not treat cancer and they do not interfere with your prescribed treatment. By helping to control symptoms and relieve stress, they may make it easier for you to endure your cancer treatments.

Types of complementary therapies include:

- acupuncture
- biofeedback
- guided imagery
- massage therapy
- meditation

- pet therapy
- yoga
- art therapy
- music and writing therapy
- tai chi

Throughout the year, Life with Cancer offers a variety of complementary therapy programs. Please visit the <u>Life with Cancer</u> or call **703.698.2526** for more information.

Please remember that some alternative therapies, such as herbal supplements and vitamins actually may interfere with standard medical treatments. They even may cause serious side effects. If you are considering using any unproven treatments, discuss this with your cancer care team.

You may also request information from: The American Cancer Society www.cancer.org 1.800.227.2345

National Cancer Institute www.cancer.gov 1.800.422.6237

## **My Financial Information**

## **Billing Information**

Your specific cancer experience will determine the type and number of medical visits you make. Providers who may bill you for their services include:

- anesthesiologist
- department of radiation oncology
- genetic counselor
- hospital
- lab
- medical oncologist

- pathologist
- physical therapist
- occupational therapist
- radiation oncologist
- radiologist
- surgeon

Billing can be confusing. You may receive multiple bills related to the same service. For example, if you undergo surgery you will be billed by the surgeon, the anesthesiologist and the hospital. Or you may receive bills from providers who work behind the scenes, such as the dosimetrist who calculates the proper radiation dose for your treatment.

Providers who participate in your insurance plan will ask your permission to bill your plan directly. After your plan pays the provider, the provider will bill you for any balance. At the same time that your plan pays the provider, it sends you an Explanation of Benefits (EOB) in the mail.

The EOB is *not* a bill. It lists the services billed by the provider, what your insurance plan paid and your financial responsibility (balance). You do not owe any money until you receive a bill from your provider. Compare the bill to the EOB to make sure the balances match. Call the number on the EOB to report discrepancies.

If you belong to a secondary insurance plan, submit a copy of the bill and the EOB. Your secondary plan may pay the entire balance on your behalf. If your provider does not participate in your insurance plan, you may need to pay the provider directly and then submit the bill to your insurance plan for reimbursement.

Please note that any co-pay (the fee that you pay at the time you receive health care services) applies to each individual visit. For example, if you receive radiation therapy five days a week for six weeks, you will be responsible for 30 co-payments.

If you do not have medical insurance, you will need to make payment arrangements with each provider. Your social worker can help.

Some insurance plans require that you get a referral from your primary care provider before you can see a specialist. For example, if you complete a round of chemotherapy, and your medical oncologist wants you to see a surgeon, you will need a new referral. Please make sure to take care of this before you schedule an appointment.

Keeping track of your medical bills can eat away at your time and energy when you need to focus on getting better. It may be helpful to appoint a loved one to keep track of your bills.

Here are other suggestions to simplify the process:

- log every visit in "My Treatment Diary" section included in this journal
- write the payment date and check number on each bill you pay
- attach the Explanation of Benefits (EOBs) to the paid bill
- keep copies of bills or EOBs before submitting them elsewhere

## Glossary of Billing and Health Insurance Terms

Co-payment: flat fee that you pay each time you receive health care services

**Deductible**: amount you must pay each year for health care expenses before your health insurance plan begins covering costs

**Denial of claim**: refusal by your insurance plan to pay your claim for health care services

**Health care decision counseling**: service provided by some health insurance plans or employers to help you weigh the benefits, costs and risks of medical tests and treatments

**Lifetime maximum benefit**: maximum amount your health insurance plan will pay for all your health care services during your lifetime.

**Ancillary services**: supplemental services, such as home health care, lab tests, physical therapy and occupational therapy, which help your physicians diagnose and treat your condition

**Benefit**: amount the insurance plan pays to you (the claimant) or an assignee (for example, the physician you authorize to receive payments) after a claim has been filed

**Case management**: system used by employers and insurance plans to make sure you receive appropriate and reasonable health care services

Claim: applying for payment of benefits under a health insurance plan

**Claim form**: itemized statement of health care services and their costs submitted by you or your medical provider to your health insurance plan in order to collect payment

Claimant: person submitting a claim

**Co-insurance**: amount (usually a percentage) that you are required to pay for services, after you have met your deductible

**Maximum dollar limit**: maximum amount of money that your health insurance plan will pay for claims within a specific time period, such as one year

**Medigap policies**: health insurance offered by private companies designed to pay for some of the costs that Medicare does not cover

**Network**: physicians, hospitals and other medical care providers that a specific insurance plan has contracted with to deliver medical services to its members

**Out-of-plan**: physicians, hospitals and other health care providers who are not in the network (see above) and whose services may not be covered, or covered only in part by your insurance plan

**Out-of-pocket maximum**: predetermined limit to the amount you have to pay out of your own pocket for health care services during a set time period

**Outpatient care**: treatment you receive without an overnight stay in a hospital or other inpatient facility (your health insurance plan may require that certain tests and procedures, including certain surgery, be performed on an outpatient basis)

**Preferred provider organizations (PPOs):** pre-selected group of health care providers (network) that offer services at a discounted rate

**Primary care provider (PCP)**: health care professional responsible for overseeing your overall health care needs

**Provider**: professionals, including physicians, hospitals, nurse practitioners, chiropractors, physical therapists and others, who provide medical treatment

**Referral**: written authorization from your primary care provider for you to see a specialist, required before your health insurance plan will cover the fee

**Second opinion**: medical opinion provided by a second physician or medical expert, after you receive a diagnosis or recommendation for treatment

**Usual, customary and reasonable fees**: average fee charged by a particular type of healthcare provider within a geographic area

**Waiting period**: time during which you are not eligible to receive benefits from your health insurance plan

#### Resources

## **Internet & Community Resources**

As you move through your cancer experience, you may want to learn as much as possible about your disease and its treatment. One source to turn to is the Internet.

In keeping with its commitment to provide comprehensive services to people with cancer. Inova has devoted a large section of its website to cancer topics at www.inova.org/cancer which features the following information and resources that can support you through your cancer journey:

At <a href="https://www.inova.org/cancer">www.inova.org/cancer</a> you can also learn more about:

- treatment services
- treatment locations
- support services
- services for women and children
- finding a cancer doctor
- Life with Cancer

On the Life with Cancer Web site, located at www.lifewithcancer.org you will find a wealth of information about educational and support services and programs available to you. The site features a monthly calendar that allows you to register for classes and events online.

As you continue searching the Internet, please remember that not all the information is up-todate or reliable. Some sites are based on only personal experience. Many sites contain information that is medically unsound and may even be harmful. Fortunately, many highly respected government, educational and private organizations share valuable information through their Web sites.

#### **General Resources**

American Cancer Society	1-800-ACS-2345	www.cancer.org
Capital Hospice	1-866-545-6964	www.capitalhospice.org
Greater Washington Coalition for Cancer Survivors	s 202-364-6422	www.gwccs.org
National Cancer Institute,	1-800-422-6237	www.cancer.gov
Social Security Administration	800-772-1213	www.ssa.gov
<b>Breast Cancer Resources</b>		
BreastCancer.org		www.breastcancer.org
Living Beyond Breast Cancer	1-888-753-5222	www.lbbc.org
Look GoodFeel Better	700 000 5550	
LOOK GOOd OOI BOROI	703-938-5550	

National Lymphedema Network	1-800-541-3259	www.lymphnet.org
Reach to Recovery	1-888-227-6333	
(American Cancer Society Regional Center)		
Susan G. Komen Breast Cancer Foundation	1-877-465-6636	www.komen.org
Susan Love, MD		www.SusanLoveMD.com
Network of Strength	312-986-8338	www.NetworkofStrength.org
Brain Cancer Resources		
American Brain Tumor Association	800-886-2282	www.abta.org
National Brain Tumor Foundation	800-934-2873	www.braintumor.org
Colon Cancer Resources		
Colon Cancer Alliance Helpline	877-422-2030	www.ccalliance.org
Lung Cancer Resources		
Lung Cancer Alliance	1-800-298-2436	www.lungcanceralliance.org
Alliance for Lung Cancer Advocacy	1-800-298-2436	www.alcase.org
American Lung Association	1-800-548-8252	www.lungusa.org
Lung Cancer Online		www.lungcanceronline.org
<b>Prostate Cancer Resources</b>		
American Urological Association Foundation	1-800-828-7866	www.auafoundation.org
Prostateinfo.com		www.prostateinfo.com
Prostate Cancer Foundation	800-757-2873 <u>www.</u>	prostatecancerfoundation.org
Us Too International	1-800-808-7866	www.ustoo.com
Virginia Prostate Cancer Coalition	703-339-0508	www.vapcacoalition.org

## **Glossary of Cancer Terms**

**Adjuvant treatment**: treatment that is added to another therapy or treatment to make it more effective, for example, radiation therapy following surgery

Alopecia: loss of hair from the scalp or body

**Anemia**: abnormally low number of red blood cells, which could cause lack of energy and fatigue

Anti-emetic: medication that prevents or relieves nausea and vomiting

Antineoplastic: a drug that prevents, kills or blocks the growth and spread of cancer cells

**Biopsy**: removal and examination, by a pathologist, of small amounts of tissue to diagnose disease

Bone marrow transplant (BMT) and peripheral blood stem cell transplantation: replaces bone marrow or stem cells destroyed by chemotherapy and radiation therapy

**Brachytherapy**: internal radiation therapy using an implant of radioactive material placed directly into or near the tumor

**Cancer**: general term for a number of diseases characterized by uncontrolled growth of abnormal cells that can invade nearby tissues or spread though the bloodstream and lymphatic system to other parts of the body

**Catheter (intravenous catheter)**: thin tube placed in a blood vessel to provide a pathway for drugs or nutrients

Catheter (urinary catheter or foley catheter): a thin tube placed in the bladder to drain urine

**Chemotherapy**: treatment of cancer with anticancer drugs; drugs can be delivered orally, topically, through an injection, or through an intravenous injection

**Clinical trial**: a research study involving patients designed to find better ways to prevent, detect, diagnose or treat cancer and to answer scientific questions

Complete response (complete remission) (CR): disappearance of all signs of cancer

CT scan (computerized tomography or CAT scan): X-ray procedure that uses a computer to produce detailed pictures of a cross-section of the body

**Cure**: disappearance of all signs of cancer for a period of time long enough to suggest it will not recur

**daVinci**®- robotic technology that allows a surgeon-for certain types of cancer- to make a series of very small incisions instead of a traditional larger incision. Benefits may include a shorter hospital stay, fewer complications, less scarring and a faster return to normal activities.

**Dietitian (also registered dietitian or nutritionist)**: professional who helps patients learn about the proper nutrition they need, especially while undergoing treatment

**Dosimetrist**: specialist who calculates the exact dose of radiation for each patient

**Electron beam**: stream of small, negatively charged particles found in atoms that can deliver radiation therapy

**External radiation**: delivering cancer-destroying, high-energy rays from a machine located outside the body

**Hematologist**: physician specializing in the study of blood and bone marrow and their diseases

**High-dose rate remote brachytherapy (HDR)**: radiation treatments given through tiny catheters placed at the tumor site and removed after treatment so that no radioactive material remains inside the patient

**Image Guided Radiation Therapy (IGRT)** – radiation therapy where the tumor can be seen and modifications to treatment can be made while the patient is on the table. The physician can focus the beam to treat cancers once considered unapproachable by radiation therapy. Trilogy and Tomotherapy are examples of machines capable of IGRT.

**Infusion**: delivery of fluids into the body through a tube placed in a vein

**Internal radiation therapy**: see brachytherapy

Intramuscular: injection into a muscle

**Intraoperative radiation**: external radiation given during surgery to deliver a large dose of radiation to the tumor site and surrounding tissue

**Intravenous**: injection into a vein

**Intensity Modulated Radiation Therapy (IMRT).** A 3-dimensional radiation therapy that uses computer-generated images to show the size and shape of the tumor. Thin beams of radiation of different intensities are aimed at the tumor from many angles. This type of radiation therapy reduces the damage to healthy tissue near the tumor

**Lesion**: an area of abnormal tissue change

**Leukemia**: cancer of the blood-forming tissues (bone marrow, lymph nodes, spleen)

**Leukopenia**: decreased number of white blood cells

**Linear accelerator (mega-voltage (MeV) linear accelerator or linac)**: machine that uses electricity to form a stream of fast moving subatomic particles to create high-energy radiation to treat cancers

**Lymphedema**: swelling that results from excess fluid collecting in tissues of the arm or leg after lymph nodes in the underarm or groin are removed or irradiated; also can be caused by an obstruction blocking the proper flow of lymph fluid

**Lymph nodes**: Hundreds of small, bean-shaped organs, located in the abdomen, chest, groin, neck and underarms that can trap bacteria or cancer cells traveling through the body in tissue fluid (lymph); lymph nodes act as the first line of defense against infections and cancer

Lymphoma: cancer that occurs in lymphatic system

Malignant: a tumor containing cancer cells that can spread to other parts of the body

**Medical oncologist**: physician specializing in treating cancer with drugs

Melanoma: cancer of the cells that produce pigment in the skin or the retina of the eye

Metastasis: spread of cancer cells from the first cancer site to another part of the body

**MRI** (magnetic resonance imaging): using powerful magnets and radio frequency signals instead of X-rays to produce detailed pictures of a cross-section of the body

**Mucositis**: inflammation of the lining of the mouth or gastrointestinal tract

Myelosuppression: decrease in bone marrow production of red cells, white cells and platelets

**Neoadjuvant treatment**: therapy given prior to definitive surgery or radiation

**Neutropenia**: decreased number of neutrophils (a type of white blood cell)

**Nodule:** small solid mass that may be malignant

**Oncologist**: physician specializing in the treatment of cancer

**Ostomy:** a surgically created opening in the body for the discharge of body wastes

Palliative care (palliation): treatment that relieves symptoms, such as pain, but does not cure

Pathologist: physician who studies tissue and body fluid to determine if there is disease

**Platelets:** blood cells that help form clots to control bleeding; the number of platelets may be reduced during chemotherapy

**Prognosis:** prediction of the course a disease is expected to run

Protocol: a treatment plan: also, guidelines that establish how a clinical trial will run

**Radiation:** energy carried by waves or a stream of particles directed at a specific location to damage or kill cancer cells

Radiation oncologist: physician specializing in treating cancer with radiation

**Radiation physicist**: professional who consults with the radiation oncologist to determine the most appropriate treatment schedule for each patient and is responsible for the equipment delivering the precise amount of radiation to the treatment site

**Radiation therapist**: professional who operates the equipment that delivers radiation therapy or treatment

Radiation therapy: treatment with external or internal high-energy rays to destroy cancer cells

Radioactive implant: a source of high-dose-rate radiation that is placed into or near a tumor

**Recurrence**: reappearance of cancer cells at the original site after a period during which the patient was cancer-free

**Red blood cells:** blood cells that carry oxygen from the lungs to the rest of the body

Regression: shrinkage of tumor growth

Remission: partial or complete reduction in the signs and symptoms of cancer

**Respiratory Gating:** In the past, when radiation beams were aimed at a tumor, body movement from breathing had to be accounted for and often resulted in a larger treatment area. With respiratory gating, radiation treatment is timed to an individual's breathing pattern, helping to target the tumor more precisely.

Sarcoma: cancer in bone or muscle tissue

**Simulation**: process used to plan radiation therapy that involves precisely locating and marking the target area to be treated

**Social worker**: professional trained to counsel people and their families about emotional or physical needs and to find support services for them

**Stage:** describes how far cancer has grown or spread in the body to group cancer cases into four stages denoted by Roman numerals I through IV; generally stage I cancers are small localized cancers while stage IV usually represent inoperable or metastatic cancer

**Stomatitis**: temporary sores on the lining of the mouth that can be a side effect of chemotherapy or radiation therapy

**Standard treatment**: therapy based on proven effectiveness that is currently used to fight a disease

Thrombocytopenia: extremely low level of platelets, the cells that help form clots

**TomoTherapy™** - highly specialized piece of equipment that delivers image guided radiation therapy. TomoTherapy™ improves accuracy of treatment by imaging the target tissue immediately prior to treatment and adjusts for any patient movement. Because of its precision, it allows a delivery of higher dose of radiation to the target area, improving the chance that the tumor will be destroyed.

**Treatment field**: body site at which the radiation beam is aimed

**Trilogy™ Image Guided Radiation Therapy** – a linear accelerator with a built in ability to image the targeted tissue just prior to treatment. Trilogy can be used for stereotactic radiosurgery, stereotactic radiotherapy, IGRT, IMRT and respiratory gating.

**Tumor**: abnormal overgrowth of cells; tumors can be either benign or malignant

**Tumor markers**: laboratory tests to detect substances produced by tumors or the body's response to a tumor that occur in above-normal amounts in the blood, urine or body tissues of some people with certain types of cancer.

White blood cells: blood cells that help fight infection

**X-rays**: radiation that is used in low doses to diagnose disease and in high doses to treat cancer

## **Important Phone Numbers**

#### **Cancer Centers**

Inova Cancer Center – Alexandria Inova Cancer Center – Fair Oaks

703.504.7900 703.391.4901

Inova Cancer Center – Fairfax Inova Mary Elizabeth Miller Cancer

703-776-3120 **Center – Lansdowne** 

703.858.8850

## **Inova Breast Care Institute Navigators**

Inova Alexandria and Fairfax Hospital Inova Mount Vernon Hospital

703.207.4320 703.664.7488

Inova Fair Oaks Hospital Inova Loudoun Hospital

703.391.4673 703.858.8867

## **Inova Interventional Oncology Center**

Alexandria Fairfax

703.504.7950 703.205.2606

**Inova Thoracic Oncology Program** 

703.776.3777

**Gynecologic Oncology** 

703.776.2901

**Inova Neuro-Oncology Program** 

703.776.4700

**Genetic Counseling** 

703.970.3209

Life with Cancer

703.698.2526