

This Notebook Belongs To

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# My Notebook



**NAP<sup>BC</sup>**  
NATIONAL ACCREDITATION PROGRAM  
FOR BREAST CENTERS  
ACCREDITED BREAST CENTER

A **QUALITY PROGRAM**  
OF THE AMERICAN  
COLLEGE OF SURGEONS

  
**TALLAHASSEE  
MEMORIAL**  
HEALTHCARE

 Commission  
on Cancer<sup>®</sup>  
ACCREDITED  
PROGRAM

A **QUALITY PROGRAM**  
OF THE AMERICAN  
COLLEGE OF SURGEONS



# Let's discuss your Plan of Care and Possible Appointments:

**Navigation**

Navigator Name and Contact Information

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**Medical Oncology Consultation**

Orientation/Education to the Infusion Center and Treatment Appointment

Infusion Center Appointment

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**Radiation Oncology Consultation**

CT Simulation Appointment

Radiation Treatment Appointment

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UPDATED: April 2019  
Tallahassee Memorial Cancer Center  
850-431-ICAN (4226)





<b>My Health Care Contact Information</b>		
<b>Resource</b>	<b>Phone Number</b>	<b>Comments</b>
Tallahassee Memorial HealthCare	<b>850-431-1155</b>	
Tallahassee Memorial Cancer Center	<b>850-431-4226</b>	
Primary Physician		
Surgeon		
Dentist		
Cancer & Hematology Specialists: Dr. Tim Broeseker, Dr. Amit Jain, Dr. Janice Lawson, Dr. Jeannine Silberman, Dr. Karen Russell, Dr. Jayan Nair, Dr. Mitchell Peabody, Dr. Jorge Perez	<b>850-431-5360</b>	
Tallahassee Memorial Cancer Center Outpatient Infusion	<b>850-431-1712</b>	
Radiation Oncology: Dr. Philip Sharp, Dr. Raj Bendre, Dr. Ovidiu Marina	<b>850-431-5255</b>	
GYN Oncology Specialists: Dr. Amanda Stephens	<b>850-431-4888</b>	
Billing Department	<b>850-431-6253</b>	





# Your Cancer Center Team

<b>Administration/Management</b>		
Kathy Brooks, RN, BSN	Administrator	850-431-4226
Jennifer Armstrong, RN, BSN	Infusion	850-431-1712
Lynna' Graves	Radiation	850-431-4226
Sonia Lee	Cancer & Hematology	850-431-5360
Judith Clayton, RN, BSN	Cancer & Hematology	850-431-5360
<b>Patient Navigation</b>		
Amy Anderson, RN	Cancer Patient Navigator	850-431-3433
Dana Miles, RN	Cancer Patient Navigator	850-431-2465
Amanda Hardwick, MSW	Cancer Patient Navigator	850-431-4922
Annie Wood, MSW	Cancer Patient Navigator	850-431-1680
Annette Garriagn, RN	Cancer Patient Navigator	850-431-2345
Ali Kelly, RN, BSN	Cancer Patient Navigator	850-431-0566
Sandy Grischy, RN, BSN, CHPCN	Smoking Cessation	850-431-7600
Carrie Thornal, MSW	Cancer Patient Navigator	850-431-0496
<b>Survivorship</b>		
Lynn Caley, RN, BSN	Cancer Patient Navigator	850-431-0581
<b>Dietitians</b>		
Candi Boucher, MS, RD/N, CSO	Oncology Dietitian	850-431-5532
Elyzabeth Anderson, PhD, RD/N, CSO	Oncology Dietitian	850-431-3205
<b>Research/Clinical Trials</b>		
Brittany Stith, RN, BSN	Research Nurse	850-431-0673
Karen DeCardenas, RN, BSN	Research Nurse	850-431-0644





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## **What Cancer Cannot Do**

**Cancer is so limited...  
It cannot cripple Love  
It cannot shatter Hope  
It cannot corrode Faith  
It cannot destroy Peace  
It cannot kill Friendship  
It cannot suppress Memories  
It cannot silence Courage  
It cannot invade the Soul  
It cannot steal Eternal Life  
It cannot conquer the Spirit.**

**Author Unknown**



# ***Introduction***



# About Your One Notebook...

This is your One Notebook, designed with you and your family in mind. Tallahassee Memorial's Cancer Center has a Patient and Family Advisory Council (PFAC), made up of patients and families that have used our services. The members of our PFAC felt that everyone needed a central set of comprehensive information and educational materials available for their personal use. They also believed that you should have the opportunity to "personalize" this Notebook, by making it a three ring binder so that you can add things yourself (such as lab reports, pathology reports, etc.), as well as making available individual specific handouts.

This Notebook and specific handouts are also available in an electronic format for you on the TMH Website, [www.tmh.org](http://www.tmh.org). As your journey continues we hope that you will build on this information and find it extremely useful and valuable. You will be provided additional materials by different members of your healthcare team. For example, if you require chemotherapy, a nurse will give you a specific handout on your chosen chemotherapeutic agent. Also, tumor site specific information will be provided to continue the "personalization" of this notebook. We encourage you to use all of the resources available, including the National

Cancer Institute website, [www.cancer.gov](http://www.cancer.gov), the American Cancer Society website, [www.cancer.org](http://www.cancer.org), and the American Society for Clinical Oncology website, [www.plwc.org](http://www.plwc.org).

Cancer is a disease that will require you to become involved in the making of many decisions and to help chart the course for your care and healing.

We would also like to thank our PFAC Membership and many other individuals and staff that have worked to provide you with this notebook.

If we can be of any service, please do not hesitate to ask. Your feedback is always welcome to assure that we keep you in the center of our care.





# Acknowledgements/ Information

**Tallahassee Memorial Cancer Center** is the longest continuously accredited Comprehensive Community Hospital Cancer Program (CCHP) in Florida and the only such program in the Big Bend region. It ranks among the elite 134 CCHPs in the country that have achieved accreditation with commendation, a top honor awarded through the American College of Surgeon's Commission on Cancer Care.

**The Angie Deeb Cancer Unit** is a dedicated oncology unit with inpatient beds and chair outpatient suites. It is the only dedicated oncology inpatient unit in the region.

**The Radiation Oncology Department** uses leading edge technologies and board-certified radiation oncologists (physicians). Services include intensity modulated radiation therapy, brain tumor stereotactic radiosurgery, interstitial brachytherapy or "seed" therapy for prostate cancer and mammosite partial breast irradiation for breast cancer.

**The Sharon Ewing Walker Breast Health Center** is the only breast health center in the Big Bend region that provides a wide array of diagnostic and support services for the detection and treatment for breast cancer. Services include navigational services, digital mammography, and genetic education for those at risk for cancer, early diagnosis breast cancer counseling, assistance with scheduling tests, surgery and therapies, and personal fittings for breast forms, mastectomy undergarments and lymphedema garments.

**Navigation Services** for information regarding cancer navigation services, please call 850-431-ICAN (4226).

For tumor site specific information, please refer to the NCCN Practice Guidelines in Oncology in the folder of your notebook. If you did not receive these guidelines, you can find them at <http://www.nccn.org>. By selecting NCCN Clinical

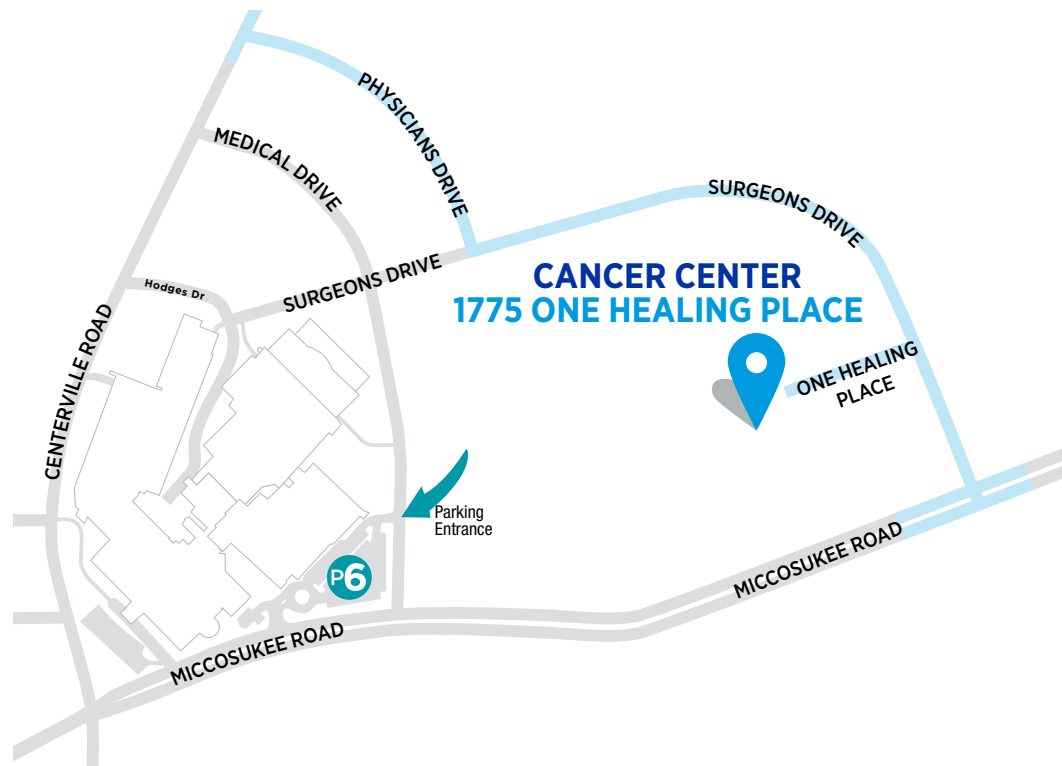
Practice Guidelines in Oncology, you will be directed to a registration page that will allow you to access the guidelines for specific cancers. These pages will be very useful to you as you go through your diagnosis and treatment.

**The latest early detection, diagnostic and cancer treatment** options are available included image guided neurosurgery, da Vinci® robotic surgery, endoscopy, X-rays (CT and MRI), Mammotone® breast biopsy system, breast reconstruction and specialization in lung cancer care.

**For more information** about the Tallahassee Memorial Cancer Center, please call 850-431-ICAN (4226) or visit [TMH.ORG/Cancer](http://TMH.ORG/Cancer).



# TALLAHASSEE MEMORIAL CANCER CENTER



## **Tallahassee Memorial Cancer Center**

1775 One Healing Place, Tallahassee, Florida

Located near the corner of Miccosukee and Surgeons Drive

## **Phone 850-431-ICAN (4226)**

We are pleased to announce that the following services are now being performed at our new Cancer Center facility:

### **TMH PHYSICIAN PARTNERS**

- Radiation Oncology Specialists
- Cancer & Hematology Specialists
- Gynecologic Oncology Specialists
- Surgical Oncology Specialists

### **TALLAHASSEE MEMORIAL HEALTHCARE - OUTPATIENT SERVICES**

OP Infusion

Navigation and Counseling Services

Survivorship Programming

Nutrition Assessments

Music Therapy

Animal Therapy

Cancer Research and Registry

Cancer Notebook



# New Patient Information

## **Tallahassee Memorial Cancer Center – Things to Know:**

- Parking is available for both patients and visitors, surrounding the center
- Wheelchairs are available for use
- Smoking is not allowed on the Cancer Center grounds

## **Support Services:**

- Music Therapy (upon request)
- Social Worker/Patient Navigator
- Registered Dietitian/Nutritionist
- Spiritual Counseling (upon request)
- Warm blankets and pillows
- Complimentary WiFi

## **Visitors and Guests – Things to Know:**

- Bathrooms are available for visitors by the elevators on the first and second floor
- Food and beverages may be purchased each day at the first floor café, until 1:30 p.m. You may bring snacks or lunch from home
- Out of respect for our patients, please refrain from bringing food with strong odors
- Out of respect and safety for other patients, we ask that there be only one visitor per patient at a time
- Children under the age of 16 are not permitted within the Center
- Cell phones are permitted, however we ask that you keep them on silent and speak quietly to avoid disrupting others
- We ask that you do not wear strong perfumes or colognes, as treatments may make some patients sensitive to smell
- Out of respect for our patient population, please refrain from entering the center if you are ill

## **For Our Infusion Patients:**

### **Preparation For Your Visit:**

- Our Outpatient Infusion Center cares for many conditions including (but not limited to) the treatment of cancer
- Please bring your medications (e.g. all home medication, “as needed” medications, vitamins, supplements etc.) or a list of all medications and list of all prior surgeries with you when you come to your appointment

### **During Your Visit:**

- Upon arrival at the Tallahassee Memorial Cancer Center, you will check in at the Registration Desk on the second floor.
- During infusion, each patient will be in their own
- individual space with a recliner, television, privacy
- curtain and a chair for one visitor
- Bathrooms are available before, during and after treatment
- Patient snacks and drinks are available, upon request
- A light lunch is served every day for patients. In order to accommodate dietary restrictions, you may bring lunch or snacks from home
- Out of respect for others, please refrain from bringing food with strong odors
- Television – please be courteous to others by keeping the volume at a low level or by using your own headphones
- Cell phones are permitted, however we ask that you keep them on silent and speak quietly to avoid disrupting others
- To help improve the patient experience, you may be mailed a brief survey
- Before leaving, you will be asked to schedule your next appointment. If not already, patients receiving chemotherapy, will be provided with education by a Nurse on course of treatment and Potential side effects associated with chemotherapy



# ***Organizing My Care***





# Organizing My Care

Learning you have cancer can trigger a wide range of emotions, including shock, fear, numbness, sadness, and even anger and betrayal. You may feel overwhelmed by your emotions or by having to make numerous decisions about your care. You may find it difficult to absorb so much new, and often confusing, information.

Tallahassee Memorial Cancer Center experts created this notebook to provide you with tools and information you need to take an active role in your care. The more you learn about your cancer and the available treatment options, the better prepared you will be to handle the challenges ahead and to make informed decisions about what is right for you. We hope this notebook helps you during your personal journey.

Don't be afraid to reach out to others during this difficult time. Your family, friends, your doctors and health care team, local cancer support groups and other organizations can provide much needed support and encouragement and play a vital role in your recovery.

The information in this section will help you plan and prepare for your treatment. However, it is not meant to replace the individual attention, advice, and treatment plan of your oncologist and medical team.

## Notebook Tips

- Keep a list of all of your doctors (a form is provided in this notebook)
- Take this notebook to every doctor's appointment and test for your reference.
- Keep records of all your visits on the form included in this section (doctor, laboratory, X-ray, etc.) Include:
  - who you spoke with
  - the date and time
  - your questions and the answers received

- Record the results of your tests and procedures
- Make note of any X-ray films you receive and where you take them so they do not get lost.
- Use the charts and forms included in this notebook to keep track of medical appointments and important information, such as your medical history and medications\*.
- Record any reactions you have to medications and treatments, as well as unusual symptoms and report them to your doctor.
- Jot down notes and questions on the blank pages.

\* In the beginning, you will be filling out many papers when you visit doctors and other health care providers. This section includes a blank medical history form and medications list you can complete and take with you to your visits. The forms are not meant to replace the papers you will be asked to fill out at your medical visits, but they will help you remember important information.

## Your Health Care Team

You will have different types of doctors, nurses and other health care providers taking care of you throughout your course of treatment and afterwards. Your health care team may include a:

**Primary care doctor:** the doctor you see for regular medical care.

**Surgeon:** the doctor who specializes in surgical procedures for cancer.

**Pathologist:** the doctor who examines tissue samples under a microscope to see if they contain cancer or abnormal cells.

**Medical Oncologist:** the doctor who specializes in chemotherapy or hormone therapy to treat cancer.

**Radiation Oncologist:** the doctor who specializes in radiation to treat cancer.

**Dentist:** The doctor you see for the diagnosis, prevention, and treatment of diseases of the teeth, gums, and related structures of the mouth, including the repair or replacement of defective teeth. A periodontist is a dentist who specializes in diseases of the gums and other structures surrounding the teeth.

**Cancer Navigators:** Through patient navigation, a registered nurse or social worker actively guides patients through the health care system. The navigator makes sure patients get needed resources and support. The navigator can effectively help patients to avoid financial, physical, social, or educational barriers to care. The Survivor Navigator will follow up and be a point of connection as you continue your journey.

**Chemotherapy/Biotherapy Oncology Nurse:** the nurse specially trained to administer chemotherapy and biotherapy medications.

**Oncology Nurse:** the nurse specially trained to care for cancer patients.

**Oncology Social Worker:** the social worker who specializes in providing counseling and other mental health services for cancer patients. They also refer patients to other support services and can provide information about helpful community resources.

**Registered Dietitian/Nutritionist:** the health care professional who can recommend diet changes to help you get the proper nutrition before, during and after your treatment.

### **Your Right to Know:**

You have the right to know—in a language you understand—as much as you want about your medical condition. However, you need to let your health care team know how much information you really want and when you are ready for the information. It can be a lot to take in at once.

You will receive information from many different people and sources. It is important to keep notes during your visits and to compare information you receive. If you have questions or receive conflicting information, share it with your doctor

who will be your main source of information. Developing a good relationship with your doctor is an important part of your care. Your doctor should make you feel at ease when sharing information, asking questions or expressing concerns.

You will feel more confident and secure in the choices you make if you understand the recommendations and explanations given to you by your doctor and other health care professionals. If you have questions, don't be afraid to ask. Many people seek a second opinion before deciding what to do about their course of treatment. Most insurance companies cover second opinions, but check with yours to be sure.

### **Lab and Test Results**

You will undergo a number of tests and studies throughout the diagnostic and treatment process. You will also consult with several physicians. It is very important to keep track of your test results and the physicians and providers for your visit.

The following tips will help reduce the stress of lost or delayed records and provide you with an ongoing record of your care.

- Ask that a copy of each test report be sent to you and all the providers on your list.
- File the reports in this notebook with the most recent report in front.

The types of reports you may receive will vary according to your type of cancer. The types of reports you may receive include but are not limited to:

- Mammogram and Ultrasound reports
- MRI, CT, and PET reports
- Blood tests
- Electrocardiogram (EKG)
- Pathology reports (often two or three different reports)
- Operative/Surgical reports

# My Doctor Visits and Tests

Date: _____ Of Doctor's Visit Or date of test, procedure, or examination	_____ Name of Person I spoke with or Name of laboratory, radiological, or other exam _____ Name of Doctor's office or Doctor who ordered examination
--	---

Results:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Question	Answer
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

Date: _____ Of Doctor's Visit Or date of test, procedure, or examination	_____ Name of Person I spoke with or Name of laboratory, radiological, or other exam _____ Name of Doctor's office or Doctor who ordered examination
--	---

Results:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Question	Answer
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

# My Doctor Visits and Tests

Date: _____ Of Doctor's Visit Or date of test, procedure, or examination	_____ Name of Person I spoke with or Name of laboratory, radiological, or other exam _____ Name of Doctor's office or Doctor who ordered examination
Results: _____ _____ _____	
Question	Answer
_____ _____ _____	_____ _____ _____
_____ _____ _____	_____ _____ _____
_____ _____ _____	_____ _____ _____

Date: _____ Of Doctor's Visit Or date of test, procedure, or examination	_____ Name of Person I spoke with or Name of laboratory, radiological, or other exam _____ Name of Doctor's office or Doctor who ordered examination
Results: _____ _____ _____	
Question	Answer
_____ _____ _____	_____ _____ _____
_____ _____ _____	_____ _____ _____

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Date: _____ Of Doctor's Visit Or date of test, procedure, or examination	_____ Name of Person I spoke with or Name of laboratory, radiological, or other exam _____ Name of Doctor's office or Doctor who ordered examination
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Results:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Question	Answer
_____	_____
_____	_____
_____	_____
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Date: _____ Of Doctor's Visit Or date of test, procedure, or examination	_____ Name of Person I spoke with or Name of laboratory, radiological, or other exam _____ Name of Doctor's office or Doctor who ordered examination
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Results:

\_\_\_\_\_

\_\_\_\_\_

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Question	Answer
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

# My Doctor Visits and Tests

Date: _____ Of Doctor's Visit Or date of test, procedure, or examination	_____ Name of Person I spoke with or Name of laboratory, radiological, or other exam _____ Name of Doctor's office or Doctor who ordered examination
Results: _____ _____ _____	
Question	Answer
_____ _____ _____	_____ _____ _____
_____ _____ _____	_____ _____ _____
_____ _____ _____	_____ _____ _____

Date: _____ Of Doctor's Visit Or date of test, procedure, or examination	_____ Name of Person I spoke with or Name of laboratory, radiological, or other exam _____ Name of Doctor's office or Doctor who ordered examination
Results: _____ _____ _____	
Question	Answer
_____ _____ _____	_____ _____ _____
_____ _____ _____	_____ _____ _____







# ALLERGIES

Allergies	Type of reaction

# SURGERIES & PROCEDURES

Surgical Procedures	Date

**Notes**









# Monthly Planner

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday



# Monthly Planner

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday







# ***Understanding My Diagnosis***



# Understanding My Diagnosis – Clinical Trials

## Voluntary Participation

During the course of your treatment you may be provided with an opportunity to enroll to one of the clinical trials or registry studies our cancer center has to offer. Participation in clinical trials is always voluntary. You will not be enrolled in a clinical trial without your permission.

## What is a Clinical Trial?

A clinical trial is a research study designed to answer one or more questions about how a certain drug, treatment or medical device affects a disease. Some clinical trials compare existing treatments to determine which is better. The current, approved treatments are called the “standard treatments.” Sometimes clinical trials are used to study different ways to use the standard treatments so they will be more effective, easier to use, and/or decrease side effects. There are potential benefits to participating in a clinical trial, as well as potential risks.

These benefits and risks are different for each clinical trial. You should discuss them with your own doctor, as well as with the clinical trial’s research team.

## Is Participating in a Clinical Trial Right for Me?

The treatment you receive during a clinical trial may help you. Clinical trial participants receive either the standard of care (what scientists and researchers consider the most effective known treatment available) or the new drug or treatment being considered. Newer therapies may lead to better results. On the other hand, they may not be any better, or even as good as, standard therapies already available.

Participating in a clinical trial will require some extra time on your part. The research team will want to monitor you closely during the trial and collect follow up information. This care is in addition to the care you will continue to receive from your oncologist and medical team.

## Am I Eligible for a Clinical Trial?

Not everyone is eligible to participate in every clinical trial. Each clinical trial has criteria about who can participate, such as the stage of your cancer, previous treatment history and other medical conditions. These factors are not meant to reject participation; they are used to ensure that researchers will be able to answer the questions they plan to study. Your doctor will determine if you are eligible for a clinical trial after a physical examination and a review of your health history and medical records.

## Considering a Clinical Trial

If you are eligible for a clinical trial, members of your research team will meet with you to discuss a number of issues as part of the informed consent process. They will also provide you with a written document called an informed consent form. You will be given time to read this document and talk it over with your doctor, family or friends before deciding if you want to participate. The consent form will answer a number of questions, including:

- What is the purpose of the clinical trial?
- How long will the trial last?
- What is required of you to participate in this study?
- What treatments or drugs will you receive during the trial?
- What treatments, tests and/or procedures will be required during the study? How many and how often?
- Which treatments, tests, medications and/or procedures will be paid for?
- What are the risks and benefits of participating in this research study?
- What treatment would be recommended for you if you do not participate in the trial?

## Questions to Ask About Clinical Trials

- Why is this study being done?
- What is likely to happen in my case if I decide to participate/not to participate?
- What are my other options (standard treatments, other studies)? What are their advantages and disadvantages?
- What were the results of any previous studies of this treatment?
- What kinds of tests and treatments does the study involve? How often are they done?
- Will this require extra time commitment on my part?
- Will I continue to be under the care of my doctor, or will I be seeing a different one (or both)?
- Will I have to travel somewhere to receive treatment? Will I be compensated for travel expenses?
- How could the study affect my daily life?
- Will I still be able to work/go to school?
- What side effects might I expect from the study treatment? (Remember that there can also be side effects from standard treatments and from the disease itself.)
- Will I have to be hospitalized? If so, how often and for how long?
- Will I have any costs? Will any of the treatments be free? Will insurance cover the rest?
- If I am harmed as a result of the research, what treatment will I be entitled to?
- How long will the study last?

Can I choose to continue to get this treatment, even after the study ends?

- Are there other sources of information about the study (for example, the Internet)?
- Are there others participating in the study I should speak to?

## More Information on Clinical Trials

You can ask your doctor or health care team for specific information regarding clinical trials available in your area.

You can also contact the National Cancer Institute (NCI) at 1-800-4-CANCER or [clinicaltrials.gov](http://clinicaltrials.gov) for a comprehensive list of ongoing clinical trials.

### Cancer Clinical Trials

A clinical trial is a research study designed to answer one or more questions about how a certain drug, treatment or medical device affects a disease. There are potential benefits to participating in a clinical trial, as well as potential risks.

These benefits and risks are different for each clinical trial. You should discuss them with your own doctor, as well as with the clinical trial's research team.

You can ask your doctor or health care team for specific information regarding clinical trials available in your area. You can also contact the National Cancer Institute (NCI) at 1-800-4-CANCER or [clinicaltrials.gov](http://clinicaltrials.gov) for a comprehensive list of ongoing clinical trials.

### For more information, please contact:

Brittany Stith, RN, BSN, OCN  
850-431-0673  
[Brittany.Stith@TMH.ORG](mailto:Brittany.Stith@TMH.ORG)

Karen deCardenas, RN  
850-431-0644  
[Karen.deCardenas@TMH.ORG](mailto:Karen.deCardenas@TMH.ORG)

# Welcome to PRE-ACT!

## Oncologist-approved cancer information from the American Society of Clinical Oncology

PRE-ACT (Preparatory Education About Clinical Trials) is an educational program designed to provide general information about clinical trials. PRE-ACT was developed with support from the National Cancer Institute (NCI) to help patients better understand what clinical trials are and how they work. PRE-ACT delivers clinical trial information through a series of short videos. You may view the entire library of these videos, or choose to have PRE-ACT personalize your videos based on your feedback.

To receive personalized videos, you will need to create or login in your Cancer.Net account. Having an account allows you to stop and return to the process as often as you need.

A Cancer.Net account requires you to provide an email address, username, and password. This information is only used for accessing specific Cancer.Net features, such as PRE-ACT, and you will not receive emails from ASCO.

We appreciate your interest in PRE-ACT and hope to provide you with useful information that may help you in considering all of your treatment options.

Please click “Start” to begin the PRE-ACT educational program. If you already have a Cancer.Net account, please click the “Returning Visitor” button to log in and continue.

### Links:

<http://www.cancer.net/navigating-cancer-care/how-cancer-treated/clinical-trials/pre-act>





# Hereditary Cancer

Brought to you by the National Society of Genetic Counselors , Cancer Special Interest Group

## FACT SHEET

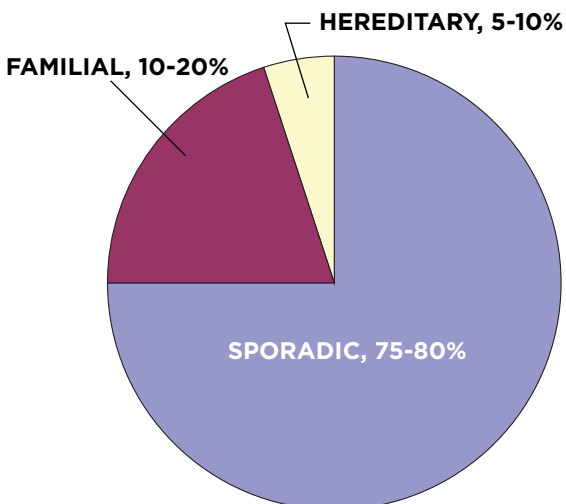
### Overview

Cancer is a relatively common diagnosis in the general population, and the majority of cancers are not due to inherited (genetic) factors. When cancer develops because of genetic factors, or mutations, individuals carrying these genetic mutations present with often very high risks of cancer. In addition the cancer tends to occur at a younger age than in the general population. While hereditary cancer syndromes account for a minority of cancer diagnoses, it is important that they are identified as general population screening is not adequate.

### What Percentage of Cancer is Hereditary Cancer?

Underlying etiologies of cancer are generally thought to fall into three different categories including:

- Sporadic - the cancer is likely due to several factors (largely environmental) with increasing age being the largest risk factor
- Familial/Multifactorial - Where there is a clustering of cancer in the family likely due to several genetic and environmental factors shared amongst family members
- Hereditary - the cancer in the family is due to a single gene alteration predisposing members of the family Who carry the alteration to a significantly higher risk of cancer than observed in the general population



### Genetics and Inheritance of Hereditary Cancer

Genes are the instructions for the body; they provide the cell with information about how to grow, develop, and perform its normal functions. When a gene's code contains a change, called a mutation, the normal cell function is impaired. Thus in some instances, gene mutations can lead to disease. Hereditary cancer syndromes can be due to mutations in many different genes and these mutations predispose individuals to increased risks for cancer.

Each person has two copies of every gene. One copy is inherited from their mother, and one copy is inherited from their father. Mutations causing hereditary cancer syndrome can be passed down through the family by both men and women. The risk to children of an individual with a hereditary cancer syndrome depends on the function of the specific gene carrying a mutation.

For many hereditary cancer syndromes, genetic testing is available to help confirm whether a family has a mutation in a known gene. If a mutation is found, this confirms the diagnosis of a particular hereditary cancer syndrome and allows other at-risk relatives to be tested for the specific mutation.

To find a genetic counselor near you, go to [www.nsgc.org](http://www.nsgc.org)

## Medical Management

There are interventions available for most individuals with a diagnosed hereditary cancer syndrome to address the increased cancer risks by following specialized cancer prevention and early detection guidelines. These interventions can often include a range of recommendations and options, such as regular screening, preventive surgery and certain medications. When possible, individuals with hereditary cancer syndromes should seek management with physicians or centers who are experienced with this condition.

## When to consider Evaluation for Hereditary Cancer

Reviewing family history information with a genetic counselor can help determine the chance that a family has a hereditary cancer syndrome that may be predisposing individuals to cancer.

Features in the family history which may suggest a hereditary cancer syndrome:

1. Several family members with the same or related forms of cancer, often in multiple generations
2. Cancer occurring at a young age of onset
3. Individuals with bilateral or multiple primary tumors
4. Rare cancers or cancer in the less commonly affected sex (such as male breast cancer)
5. A lack of environmental risk factors

## Genetic Counseling

The diagnosis of a hereditary cancer syndrome can be complex with the features of a family history possibly representing multiple hereditary cancer syndromes (and therefore other genes). In addition the cancers in a family may be due to a combination of genetic and environmental factors. For this reason, a detailed review of the family history by a genetics professional is important before pursuing any type of genetic testing. Genetic test results can be complicated and are most useful when interpreted by a genetics professional in the context of an individual's complete personal and family history.

It is important to consider both the pros and cons of genetic testing before pursuing such tests. A genetic counselor can help to identify and explain issues that should be considered regarding genetic testing. A genetic counselor also can help determine which, if any, genetic tests may be helpful for a family.

To locate a genetic counselor near you, please visit [www.nsqc.org](http://www.nsqc.org) and click on the 'Find a Genetic Counselor' link.

## Genetic Discrimination

The Genetic Information Nondiscrimination Act (GINA) was signed into federal law in 2008. GINA prohibits health insurers and most employers from discriminating against individuals based on genetic information (including the results of genetic tests and family history information). According to GINA health insurance companies cannot consider genetic information to be a preexisting condition, nor can they use it to make decisions regarding coverage or rates. GINA also makes it illegal for employers to use genetic information in making decisions about hiring, firing, promotion or terms of employment. It is important to note that GINA does not offer protections for life insurance, disability insurance, or long-term care insurance. More information about GINA can be found by contacting a local genetic counselor or by visiting [www.ginahelp.org](http://www.ginahelp.org).

## Tallahassee Memorial Clinical Genetics Center

If you are interested in having a consultation to discuss your personal and/or family history of cancer and genetic testing options please ask your physician for a referral to the Tallahassee Memorial Clinical Genetics Center. This clinic is staffed by Laura Martin, MD a clinical geneticist and Katie Farmer, MS, CGC a certified genetic counselor.

Tallahassee Memorial Clinical Genetics Center  
3333 Capital Oaks Drive  
Tallahassee, FL 32308  
Ph- 850-431-4041  
Fax- 850-431-4471 for referrals)

To find a genetic counselor near you, go to [www.nsgc.org](http://www.nsgc.org)

# ***My Plan of Care***



# Surgery Options and Postoperative Care

Depending on the type and stage of your cancer, you may need surgery to effectively treat your cancer. The following information covers different surgery options your doctor and health care team may discuss with you. It also includes tips on how to care for yourself after surgery. If the information included here differs from what your individual surgeon recommends, follow your surgeon's directions. If you have questions, don't hesitate to ask your doctor or health care team. In certain instances your doctor may recommend that you have neoadjuvant chemotherapy. Neoadjuvant chemotherapy is chemotherapy given before surgery to shrink the cancer, which may allow a person with a larger cancer to have to surgically remove the tumor or improve the results with other surgical options.

The information in this section will help you plan and prepare for your treatment. However, it is not meant to replace the individual attention, advice, and treatment plan of your oncologist and medical team.

## Surgery

During a surgery, a surgeon will remove the cancer and a small amount of normal tissue surrounding it. The amount of tissue removed depends upon the size of the cancer. The surgery is usually done on an outpatient basis.

The tissue removed during the surgery will be sent to the pathology lab after surgery. The pathologist will make a detailed description of what the cancerous cells look like and how they react. The pathologist will also determine if there are cancer cells at or very near the edge (or margin) of the tissue removed. If cancer cells are found at or near the edge, the surgeon may recommend a second, larger surgery if that is the best option.

If no cancer cells are found at or near the edge, you may start radiation therapy once you have healed from the surgery or have completed your chemotherapy, if chemotherapy is recommended.

## Lymph Nodes

Lymph nodes are small bean-shaped structures that run close to your vascular system (arteries and veins) and are part of the lymphatic system running throughout your body. An important part of your immune system, this elaborate network of vessels and nodes helps fight infection and clean up waste products made by the body. However, if cancer cells invade these lymph nodes, they can spread to other parts of the body.

## Wound Dressing and Drain Care after Your Surgery

When you go home, you may have a dressing over your incision or wound where the surgery was done. You may also have Jackson-Pratt drains (JP drains) for a few days or week after your surgery. Below are some general care guidelines. Your surgeon will give you more specific instructions on how to care for your dressings and drains. (If these instructions differ from what your individual surgeon recommends, follow the directions from the surgeon's office.)

- Check your incisions every day. If your incision/wound is healing well, without drainage, then you do not have to place a dressing over it.
- If you do have dressings over the incision/wound, make sure that the dressing stays clean and dry. Change dressing daily or as needed. If there is a change in the amount or color of drainage, contact your surgeon.
- Your surgeon will let you know if you can take a shower. If you are allowed to shower, wash incision/wound gently with soap and water. Avoid rubbing the incisions or soaking in the bathtub. Pat them dry and do not use ointments, creams, or lotions on the incision.
- It is normal for your incision to bruise, itch, burn, feel tight, or have some swelling. If you notice a change in the appearance of the incision/wound, call your surgeon.

**Symptoms to watch for include:**

- redness around the wound
- leakage of clear, bloody, or white fluid
- large amount of swelling
- excessive warmth around the wound
- fever

If any of these symptoms develop, or you notice a change in your incision/wound since discharge, contact your surgeon.

**Activities after surgery**

The time it takes to return to normal activities after surgery depends on the type of surgery performed. Always discuss with your surgeon before resuming any activity.

**General guidelines**

When you first return home, you should be able to do much of your own personal care, such as bathing, dressing, preparing simple foods, etc. You may find that you need to take rest breaks between activities, but you should not stay in bed for prolonged periods during the day. A short walk each day will help your recovery.

You can resume light household and work activities such as simple meal preparation, folding laundry, using your computer and completing paperwork as you feel ready. Avoid activities that require moderate to heavy lifting (grocery shopping) or pushing/pulling (vacuuming) and repetitive motions. A good rule during this time is to listen to your body, do what is comfortable, and stop and rest when you feel tired.

**Driving**

Your surgeon will let you know when you may be able to resume driving. You should not be driving as long as you are on pain medications. A pillow or seat belt positioning device may help cushion or adjust the seat belt to a more comfortable position when you drive.

**Returning to work**

Most people are ready to return to work within several weeks after their surgery. Again, this time frame depends upon the extent of the surgery and the type of work you do. Another option may be to return to work part-time, gradually adding additional hours as you feel ready. Your doctor will help you determine what is best for you.

# Breast Cancer-Related Lymphedema

Lymphedema is an abnormal accumulation of lymphatic fluid in the space between the cells just under the top layer of skin affecting the arm(s) and chest most often. This abnormal accumulation of fluid in the arm(s) and chest can be the result of changes done to the lymphatic system as the result of surgery and/or radiation.

We do not know why one woman may develop lymphedema after breast cancer treatment while another, who has the same treatment, may not. Sentinel lymph node biopsy has been proven to lower the risk of developing lymphedema; however it does not prevent it entirely.

Increased risk factors for upper extremity lymphedema should be identified:

- Breast surgery with **axillary lymph node dissection**
- **Obesity is a well known contributing factor to the development of lymphedema**

**ALL PATIENTS WITH AN AXILLARY LYMPH NODE DISSECTION SHOULD BE REFERRED TO A CERTIFIED LYMPHEDEMA THERAPIST.**

Basic guidelines might lower your risk of developing lymphedema:

- **Avoid injury/Infection.** Have blood drawn, IVs and shots done in your unaffected arm.
- **Clean and protect skin and nails, using lotion, sunscreen, and insect repellent.**
- **Avoid constriction or squeezing of the arm.** Have blood pressures taken on the unaffected arm. Avoid tight or binding clothing or jewelry.
- **Wear a compression sleeve, garment, or bandages when you fly and perform strenuous exercise or activities.**
- **Increase the level of exercise gradually and build up duration of any new activity slowly.**

Signs of lymphedema:

- Swelling in the breast, chest, shoulder, arm or hand
- Area feels full or heavy
- Skin changes texture, feels tight or hard, or looks red
- New aching or discomfort in the area

Lymphedema treatment:

- Treated by an Occupational or Physical Therapist with special training in Lymphedema (Certified LymphedemaTherapist)
- Complete Decongestive Therapy (CDT) - compression sleeve
- Manual lymphatic drainage (MLD) - is a type of massage

## REFERENCES:

National Cancer Institute at the National Institutes of Health (PDQ Study)  
American Cancer Society  
Oncology Nursing Society  
Living Beyond Breast Cancer  
National Lymphedema Network





# Medical Oncology

Medical oncology is the study and treatment of cancer using chemotherapy and hormone therapy. A medical oncologist is an internal medicine doctor with special training in cancer treatment. Many medical oncologists are also specialists in hematology (study of the blood). Their responsibilities may include:

- Managing the care of cancer patients needing chemotherapy and hormones,
- Referring patients to and consulting with other physicians and health care providers for additional tests or procedures, and
- Referring patients to community resources and clinical trials as appropriate

## Chemotherapy

Chemotherapy or “chemo” treats cancer using different chemicals (medications), which are also known as:

- Anti-cancer drugs
- Anti-neoplastic agents
- Chemo drugs
- Biotherapy
- Hormones

Usually given in combination, these drugs target cancer cells that are growing or dividing. They can also affect normal, healthy cells.

Since cancer is a word to describe many different diseases, there is no one type of treatment that is used universally. Chemotherapy is used for a variety of purposes:

- To cure a specific cancer.
- To control tumor growth when cure is not possible.
- To shrink tumors before surgery or radiation therapy.
- To relieve symptoms (such as pain)
- To destroy microscopic cancer cells that may be present after the known tumor is removed by surgery (called adjuvant therapy). Adjuvant therapy is given to prevent a possible recurrence.

## Chemotherapy Terms

Chemotherapy encompasses a wide variety of therapy treatments. Terms such as “adjuvant,” “neoadjuvant,” “consolidation,” and “palliative” often add to the confusion surrounding chemotherapy if not properly defined and explained. The purpose of this page is to increase the level of understanding about various chemotherapy protocols currently used.

**Adjuvant chemotherapy** - Chemotherapy given to destroy left-over (microscopic) cells that may be present after the known tumor is removed by surgery. Adjuvant chemotherapy is given to prevent a possible cancer recurrence.

**Neoadjuvant chemotherapy** - Chemotherapy given prior to the surgical procedure. Neoadjuvant chemotherapy may be given to attempt to shrink the cancer so that the surgical procedure may not need to be as extensive.

**Induction chemotherapy** - Chemotherapy given to induce a remission. This term is commonly used in the treatment of acute leukemias.

**Consolidation chemotherapy** - Chemotherapy given once a remission is achieved. The goal of this therapy is to sustain a remission. This term is commonly used in the treatment of acute leukemias.

**Maintenance chemotherapy** - Chemotherapy given in lower doses to assist in prolonging a remission. Maintenance chemotherapy is used only for certain types of cancer.

**First line chemotherapy** - Chemotherapy that has, through research studies and clinical trials, been determined to have the best probability of treating a given cancer.

**Second line chemotherapy** - Chemotherapy that is given if a disease has not responded or reoccurred after first line chemotherapy. Second line chemotherapy has, through research studies and clinical trials, been determined to be effective in treating a given cancer that has not responded or reoccurred after standard chemotherapy.

**Palliative chemotherapy** - Palliative is a type of chemotherapy that is given specifically to address symptom management without expecting to cure the cancer.

### **How Chemotherapy medications work**

Chemo drugs work actively against rapidly dividing cells in the body, such as:

- Bone marrow, which produces red and white blood cells and platelets
- Hair follicles
- The lining of the mouth, throat, stomach, intestines and rectum

Chemotherapy drugs are not selective. They cannot tell the difference between cancer cells and healthy cells, and they may destroy both. Fortunately, normal cells recover and cancer cells die. While the normal cells are recovering, you may experience some side effects. Most of these side effects can be prevented or lessened with drugs and other treatments. Your oncology nurse will discuss these with you.

### **How they are given**

Chemotherapy drugs are given intravenously (through a vein) or orally (by mouth) and travel throughout the body. They may be given before (neoadjuvant therapy) or after (adjuvant therapy) surgery to treat primary cancer.

Chemo is given in cycles, which include alternating treatment periods and rest periods. This gives normal cells a chance to recover, but does not give cancer cells enough time to multiply. Each treatment may take a few hours, depending on the type of drugs used and the length of time it takes to administer each drug. Treatments may be repeated every one to four weeks, three to six months, or longer depending on your treatment plan.

### **Side effects**

Chemotherapy side effects can range from minor to life-threatening conditions depending on the chemo drug used, the dosage, and a person's overall health. Medical professionals will inform you about all the potential side effects of any treatment they prescribe before you give your consent. These side effects are discussed in detail in the "Chemotherapy and You" book that you will receive.

Different people have different reactions to the same chemotherapy. If you undergo chemotherapy, you will not know how you will react or what side effects you will experience until a few days after your first chemotherapy session. Listen to your body, pay attention to what you are feeling, and always report symptoms to your doctor or nurse. Your initial experience will help you prepare for and cope with future chemotherapy sessions.

### **Hormone Therapy**

Some tumors use estrogen and testosterone, in women and men, to survive and grow. These tumors are called hormone-fed or hormone-responsive tumors. To determine whether a tumor falls into this category, a pathologist analyzes a sample of the tissue. If the tumor is found to be hormone-responsive, your medical oncologist likely will recommend hormone therapy in order to decrease the hormone level in your body by blocking the tumors route to the hormones it wants and needs for growth.

Cancers most likely to be hormone-responsive include:

- Breast cancer
- Prostate cancer
- Ovarian cancer
- Uterine cancer

Some forms of hormone therapy are also used to treat such cancers as lymphoma, leukemia, and multiple myeloma. Sometimes, hormone therapy also is used to shrink tumors before surgery so they are easier to remove. Medical oncologists may also recommend hormone therapy after treatments have ended to try to keep cancer from recurring.

Medical oncologists may recommend hormone therapy to prevent cancer from growing, especially in postmenopausal women since their cancer cells often have receptors that attract estrogen and /or progesterone. Pre-menopausal women may also be prescribed hormone therapy following surgery, chemotherapy, or radiation therapy.

Hormone therapy treatment options are available in several forms including surgery, radiation, and drugs.

Possible surgeries include: removal of the testicles, removal of the ovaries, or removal of the adrenal gland.

Radiation therapy can stop hormone production in the testicles, ovaries, and adrenal and pituitary glands.

Drug therapy can be used to block the access of cancer cells to your body's supply of estrogen or testosterone. Some drugs may be taken in pill form, as an injection or intravenously.

## **Other treatments**

### **Monoclonal antibodies: Targeted therapies**

The antibody is given to some cancer patients who produce an excessive amount of a protein on their cancer cells. It helps to prevent the cancer cells from growing and dividing. The antibody can be given alone or in combination with chemotherapy. Your physician will discuss this therapy with you if you are a candidate

### **Bisphosphonates**

These are drugs are given to those whose cancer has spread to their bones. Pamidronate (Aredia) and Zoledronic acid (Zometa), the two most common bisphosphonates, are given intravenously every three to four weeks to strengthen the bones and relieve pain. They also help lower blood calcium levels that sometimes increase when cancer spreads to bones. Too much calcium (hypercalcemia) can lead to changes in mental status, nausea, vomiting, constipation, bone fractures, kidney stones, and, in severe cases, coma.



# Radiation Oncology

## Initial Consultation

After registering at the front desk, a member of the nursing staff will record your height and weight and ask you about your medical condition. Since each patient and disease is different, your physician will review your records, x-rays and pathology. Your physician will then talk with you about your past and present health history and examine you. Treatment options will be discussed. If you are eligible for and considering a research study (available at TMH), members of the research staff will meet with you to explain the study and to answer any questions you may have. Prior to the beginning of radiation therapy, you will be asked to sign a consent form for treatment. The purpose of the consent form is to ensure that you understand what to expect from the treatment.

If further tests are needed, these will be scheduled, and an appointment will be set for treatment planning simulation.

Any questions you may have about insurance, social security or Medicare will be taken care of by a Patient Account Representative in our front office.

## Simulation (Treatment Planning)

“Simulation” is not a treatment but an important part of the treatment plan. It involves taking special x-rays and measurements which are used by the treatment team to outline the area of the body that is to be treated so that the radiation beam is properly positioned.

Simulation may take up to an hour and you will lie on a flat, narrow table. The area of the body to be treated may be outlined with a temporary skin marking. In a few days, these marks may be replaced by a small, permanent ink dot (tattoo) placed in the area of your treatment. This tattoo further guarantees the accuracy of treatment and saves time when and if you need to be re-marked. Sometimes, special molds **may** be made to assist in positioning during treatment. A limited CT scan of the area that is going to be treated will be performed during the simulation.

This is used to help the doctor see the area that is being treated. Treatment will not start on the same day as the simulation. You will be given an appointment to return a few days later to begin your radiation therapy.

## Treatment

Radiation therapy uses high-energy radiation to damage cancer cells so they do not continue to grow. The radiation is aimed at the tumor and the area close to it. Radiation treatments are usually given five days a week, Monday through Friday, but this may vary. Your physician will discuss the treatment plan which applies to your situation and the number, frequency and schedule of treatments will be confirmed.

Upon arriving each day, please register at the front desk. **Due to limited seating in our treatment waiting room multiple family members are asked to remain in the front waiting room.**

Delays may occur due to emergencies or machine checks, but treatment appointments usually remain on schedule, so it is important to arrive on time, 10-15 minutes before your appointment. If you need to come at a different time please notify the therapist a day or two before that treatment in order to avoid a long wait. If for any reason you are unable to keep your appointment, please call Radiation Therapy at 850-431-5255 and state that you are under treatment so that you will be transferred to the appropriate extension.

Inpatients will be treated at a time convenient to both patient and radiation therapist.

On the first treatment visit, the radiation therapist will show you the treatment room and review your treatment schedule. A port film (an x-ray picture of the area being treated) will be taken and then checked by your doctor to ensure that the treatment is accurate. Additional port films will be taken at least weekly. These films are not intended to monitor the shrinkage of the tumor, but to ensure that the radiation treatment is being delivered to the appropriate site.

The treatment is painless and similar to having an x-ray picture taken. The table may be uncomfortable but it is important to lie very still. You will be left alone in the treatment room during the actual treatment but the therapist can see you on a TV monitor and can talk with you and hear you through an intercom system.

### **Physical Evaluation**

Treatment side effects depend on the area being treated. We will discuss these with you and help manage these side effects. The nurse and physician will meet with you at least once per week during your course of radiation therapy. You will have the opportunity to ask questions at that time. Tell the radiation therapist or your nurse if problems arise at other times. If further explanation is necessary, your nurse will refer the problems to your doctor.

### **Skin Care**

Good skin care is important. Daily baths or showers are recommended with mild soap. Lotion, creams, powders, oils and antiperspirant type deodorants should not be applied in the areas being treated without a recommendation from your nurse or physician. Sun exposure should be limited during treatments and for several weeks after completion of treatment. Discuss any skin problems that arise with your nurse. You will be given specific instructions about skin care for the area that you are having treated.

# ***My Thriving***





# Coping With Cancer

While your focus will be on your physical health and all your tests and treatments, it is important not to forget about your emotional, psychological and spiritual health. They can affect your physical health and play an important part in your recovery. Remember that health is not necessarily the ABSENCE of disease; in fact, the following are some healthy ways to live WITH disease.

## 1. The Emotional “Roller-Coaster”

- It may help you to know what to expect when you first learn of your cancer. Many people experience strong feelings: shock, fear, anger, disappointment, numbness. Many are irate, disarmed, brokenhearted, furious, speechless, overwhelmed, out of control.

Keep in mind that there is no “right way” for you or your family to feel about your diagnosis, and that your family and friends will each have a different way of handling news about your cancer. For example, even though breast cancer is increasingly treatable, it is not uncommon upon diagnosis to fear death. Coping with cancer involves finding people with whom you can share these feelings, and honestly communicate with others who can provide you with up-to-date information. Also, some more tips:

- Learn to ask for help. For example, have family members or friends help you get your house ready before you have surgery or chemotherapy.

Rather than trying to “hide” your condition from your family (as if they don’t already sense something is wrong), include them in your journey by assigning them tasks to help you, such as cooking or yard work. Use these times together to answer their questions and to provide them with assurance.

Try to find someone you can reach out and open up to. It should be someone with whom you feel safe sharing your thoughts, fears, anger and hopes. Support groups also offer a safe place to share your thoughts and emotions.

## 2. What legal issues do I need to discuss with my family?

When you’ve been diagnosed with cancer, you want to concentrate on getting better and coping with your treatment. It’s also a good idea to make some important decisions with your family and doctor while you are still feeling well. Things you may want to discuss include:

- An Advance Directive This document contains written instructions specifying the type of future medical treatment to be used in the event you become unable to speak for yourself.
- A Durable Power of Attorney for Health Care This legal document authorizes another person to make health-care decisions for you if you became physically or mentally unable to make these decisions yourself.
- You can secure a form for this purpose from your healthcare provider or call- 1-888-594-7437 to receive Five Wishes, a living will form that is now recognized in 36 states.

## 3. Coping with Fear and anxiety = Learning to Manage Stress

The fear of cancer reoccurring is also a natural and very powerful response. After a cancer experience, your sense of self is altered forever. You know that you are not protected from losing your health. You may feel fearful, anxious or uneasy for a long time after your last treatment. It is important to deal with these feelings so that cancer doesn’t rob you of living your life to the fullest. Here are a few helpful tips:

- Talk about your fears and other feelings with someone you trust. Being dishonest and NOT talking about your feelings can produce an atmosphere of uncertainty and increased anxiety.

- Take control of your life. Be aware of the cancer, but don't let it dictate the way you live. For example, monitor your rest and relaxation; listen to your body, knowing that crises drain our energy, while exercise, sleep and nutrition are excellent resources for managing stress.
- Learn to say "No;" learn to laugh at yourself;
- Redirect your anxiety into energy for taking action.
- Become knowledgeable about your cancer. Knowledge is power.
- Remember to have regular check-ups, and learn to trust your healthcare providers.
- Understand that there will be days where you will have fearful thoughts. But also know that there will be days where you don't.
- Focus on the here and now. Enjoy each day and remember that life is a precious gift.

#### 4. Depression

It is common for cancer patients to experience some form of depression during their diagnosis and treatment. This is called situational depression. If you feel you are becoming depressed, please tell your doctor, nurse or therapist. They are there to help you and can offer suggestions to get you through this difficult period. Knowing that it is part of the journey may help you discover your own ways of dealing with the sadness, tears and occasional guilt that accompanies this "dark night of the soul."

#### 5. Spirituality: Suggestions for strengthening hope for you and your loved ones.

- Maintain a healthy balance between optimism and reality. Share a sense of hope with one another.
- It is common to want answers for questions like: "Why me?" and "What did I do to deserve this." Use these searches to develop a deeper relationship with God and/or your clergy.
- Find and use additional resources to deepen your sense of meaning and purpose to life.
- Find support in prayer and/or religious faith, or in your philosophy of life.
- Reflect on what has helped you cope

with previous crises in life. How did that experience impact your values, faith and sources of comfort? How were you able to "grow" through those experiences? Some people actually become stronger.

- Learn from the stories of other cancer survivors. Both you and your loved ones are encouraged to participate in support groups. How did they develop new coping skills?
- Find creative ways to bring pleasure to each day. Appreciate the beauty and wonder present in daily life. Some believe it is a gift from God.
- Find inspiration and hope in the things that bring you joy (i.e. reading, music, family, etc.) Talk about these with friends and family who will listen to you.

The late Victor Frankl, M.D., once said, "People who find meaning in their lives tend to be stronger survivors." Eleanor Roosevelt, former First Lady of the U.S. said, "You gain strength, courage and confidence by every experience in which you really stop to look fear in the face."

#### 6. Should I join a support group?

People diagnosed with cancer, and their families, face many challenges that may leave them feeling overwhelmed, afraid and alone. It can be difficult to cope with these challenges or to talk to even the most supportive family members and friends. If this is the case, you and your family may want to join a cancer support group. Cancer support groups can help you and your loved ones:

- Feel less alone.
- Improve your ability to deal with the uncertainties and challenges that cancer brings.
- Meet others experiencing the same problems and fears and discuss ways to cope.
- Find a confidential atmosphere where you can discuss the challenges of your illness or of having a loved one with cancer without feeling judged.

Sometimes, others who have been through similar experiences can explain things differently than your health care providers. Be aware, however, that others may share information or experiences that do not apply to you. Never replace your doctor's advice with that given by another patient.

## 7. Getting a good night's sleep

Despite exhaustion and fatigue from treatment and stress, between 30 and 50 percent of cancer patients report problems falling asleep. It may be helpful to:

- Keep a record of your sleeping patterns for two weeks. When do you go to bed? Do you fall asleep immediately? When do you wake up? Are hot flashes waking you up at night? Is pain interfering with your ability to sleep?
- Share this record with your doctor and come up with a "sleep plan." This may include medication and lifestyle changes.

The National Cancer Institute recommends the following to help promote rest and treat sleep disorders:

Create an environment that decreases sleep interruptions by:

- Lowering noise
- Dimming or turning off lights
- Adjusting room temperature
- Placing pillows in a supportive position
- Wearing loose, soft clothing to bed
- Eat a high protein snack two hours before bedtime.
- If you can't fall asleep or stay asleep, leave your bedroom and engage in a quiet activity in another room. Don't let yourself fall asleep outside the bedroom. Return to bed when you are sleepy.
- Maintain a regular wake-up time.
- Distract your mind. Try reading, watching a video, or listening to books on tape.
- Avoid caffeine within four to six hours of bedtime.
- Avoid the use of nicotine close to bedtime.
- Don't drink alcoholic beverages within four to six hours of bedtime.
- Avoid strenuous exercise within six hours of bedtime.

## 8. Do I need medication?

There are many situations throughout your recovery process where medication may be warranted. Any symptom that is interfering with your quality of life should be discussed with your doctor or health care provider. These may include:

- Anxiety
- Bone loss
- Constipation
- Depression
- Hot flashes
- Insomnia
- Nausea/vomiting
- Pain

You are your best advocate, so don't be afraid to speak up and talk with your doctor.

### ON COPING...

**God, please give me the strength to fight and the strength to heal. Please keep watch over my children; allow them the courage to endure the stages of my healing. Thank You for Your loving support and for the encouragement from those around me. And guard my sense of humor so I can maintain balance. Amen. (Katherine Welsh, Survivor, Pray It Forward: A Gift from a Cancer Survivor; Ligurion, Oct.2008)**



# Tips for Caregiving

Home > Coping With Cancer > Caring for a Loved One > Tips for Caregiving

Printed from <http://www.cancer.net/coping-with-cancer/caring-loved-one/tips-caregiving>

This section has been reviewed and approved by the Cancer.Net Editorial Board [2], 04/2015

Listen to the Cancer.Net Podcast: Tips on Caregiving [3], adapted from this content.

## Key Messages:

Caregiving often involves different types of support and tasks, which can be overwhelming.

There are several ways to help manage all the duties of a caregiver to help you provide effective care.

## Suggestions for being an effective caregiver

Caring for a person with cancer may seem complex and like too much to cope with at first. Depending on the person's needs, you may provide different types of support, such as:

- Emotional support
- Help with medical care
- Assist with financial and insurance issues
- Serve as the communicator between the patient and the health care team

You may find the following tips can help you become a successful caregiver:

### **Remember that caregiving is a team effort** [4].

A caregiver is a member of an important team of family members, friends, volunteers, and the health care team. Each member of the team offers different skills and strengths to provide effective care.

If you are the main caregiver, help each team member express concerns, opinions, and emotions. Also, make sure that the person with cancer has a central role in all discussions and decisions, if possible. It is very important for the person with cancer to feel like an active member in their care.

CancerCare provides a special website for caregivers called My Cancer Circle [5]. This website can help

caregivers organize the family and friends who want to help. Find other online communities for support [6].

**Create a list of tasks.** Caregiving, like any responsibility, involves tasks of varying importance. Start by making a list of all of your caregiving tasks. Then, use it to decide how to divide the tasks between friends, family, professionals, and other volunteers.

**Be proactive.** Being proactive means taking charge and planning as much as possible to prevent last-minute emergencies. This can also help provide a sense of control and order. Create schedules that list which relative, friend, or other volunteer is available when and for what tasks. Make sure that all of the caregivers involved have some time to be away without feeling guilty or concerned [7]. Long-distance caregiving takes even more planning. Find out more about how to be an effective long-distance caregiver [8].

**Be a problem solver.** To be a good problem solver, identify problems, find out what is needed, and follow through. Do not be afraid to seek advice and help from others. Look for creative solutions that work for your and the person you care for.

**Try to stay positive.** Having a positive attitude can help set the tone for all that you do. You may not have control of what happens to you, but you can change how you react. To help you cope, talk with other members of the caregiving team. You may also wish to talk with friends, religious or spiritual advisors, counselors [9], and health care professionals.

**Know yourself.** Recognize your own strengths and weaknesses as a caregiver. This allows you to set boundaries and know when to ask for help. Setting limits can help you and the person you care for. The person you care for can exercise some independence, while you get a break. It is important to recognize when you need a break so you don't feel burned out. Read more about how caregivers can take care of themselves [10].

**Consider professional and volunteer services.**

These services include professional home care, home-delivered meals, and help with everyday activities. Some community agencies have volunteers who can help with transportation or advocate for health insurance or other benefits. A local hospital or community social worker [11] is a great source for referrals to programs in your community. Learn more about different care giving options [12].

**Caring for the emotional well-being of the person with cancer**

It's important to help the person you care for maintain a sense of control. A cancer diagnosis may make him or her feel little control over life. A simple step would be to ask if you can help with a specific task or decision instead of doing it on your own.

**Communicate.** One of the caregiver's most important jobs is to communicate openly with the person who has cancer. Choose a time that is convenient for both of you to talk. Provide assurance that he or she will be a central part of all discussions and decisions. Be open to the person's feelings and opinions and allow enough time to fully explain your feelings.

**Accept the limitations of a person who is seriously ill.** A person who just received chemotherapy may not be able to taste a meal you worked hard to prepare. Or, a person on pain medication may not notice all of the small things you do. Also, be aware that caregiving tasks may change as the person's health changes.

**Include the person with cancer in activities that provide meaning or pleasure.** Even if the person with cancer is no longer able to actively participate in activities he or she enjoys, look for other ways to encourage involvement. It is important to help the person stay connected to the world beyond the cancer and to maintain a sense of normalcy.

**Participating in medical and physical care****Gather details about the patient's diagnosis, treatment, and prognosis, which is the chance of recovery.**

As a caregiver, learn more about cancer, including the patient's type of cancer [13]. Many patient advocacy groups [14] also can provide information related to specific cancers. Ask the doctor about other trusted resources. In addition, you may want to keep a record of medical appointments, test results, medications and dosages, symptoms and side effects, questions, and names and numbers for resources. Find out more about managing a patient's care [15].

**Be an advocate.** Take an active role in the patient's medical care. If possible, go with him or her to all medical appointments. It is helpful to write down questions for the doctor beforehand and to write down answers. In addition, give the doctor any new information that helps him or her make informed decisions. Learn more about communicating with the doctor [16].

**Learn how to provide proper physical care.**

Some patients may need you to provide physical care such as bathing, dressing, feeding, using the toilet, and grooming. For help, talk with the health care team, watch health care videos, or read manuals or books that explain how to do these tasks. You may also want to hire professional help for these tasks if possible.

**Addressing legal and financial issues**

**Ask for an insurance case manager.** Many insurance companies will assign a person to help manage insurance concerns for a person with a serious illness. This person can help you learn what is covered by insurance, how to handle insurance issues, and find home care. Learn more about health insurance [17].

**Determine financial status.** Providing care for a person who is seriously ill can be financially challenging. Ask who will perform medical services and how specific services, such as medications or therapy, will be paid. Knowing the financial status of the patient can help guide future health care choices. Some community organizations may provide financial assistance for caregiving-related and treatment issues [18].

**Have legal documents in place.** Legal documents called advance directives [19] are an effective, legally binding way to communicate a patient's wishes. A health care proxy is a person who can legally make health care decisions on another person's behalf. A health care proxy can be designated to speak for the patient when he or she cannot.

Early on, each patient should decide who will be a health care proxy. He or she should also tell professionals involved in care who their health care proxy is. A patient may also need documents, such as a durable power of attorney for health care and a living will.

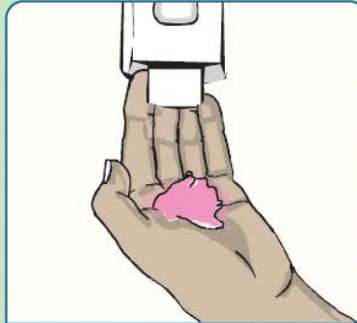




# FIGHT GERMS BY WASHING YOUR HANDS!



**1** Wet your hands



**2** Soap



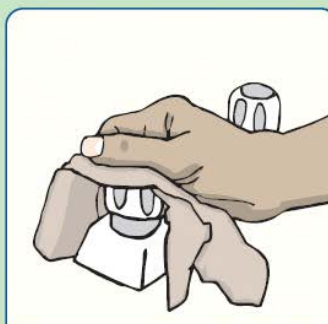
**3** Lather and scrub - 20 sec



**4** Rinse - 10 sec



**5** Dry your hands



**6** Turn off tap

## DON'T FORGET TO WASH:

- between your fingers
- under your nails
- the tops of your hands



# Nutrition During My Cancer Treatment

## What do I need to know?

A cancer diagnosis is a life-changing event that affects many aspects of your life. Nutrition is no exception. It is normal to have new concerns about nutrition after a cancer diagnosis.

Eating well will help keep you strong and supply you with the nutrients your body needs. You may, or may not, have nutrition related problems before, during, or after your cancer treatment. Nutrition needs and potential side effects vary from person to person based on: (1) Diagnosis and location of disease, (2) Previous Medical History, and (3) Type of Cancer Treatment (radiation, surgery, oral medications, or infusion cancer drug therapy).

### **Getting adequate nutrition and hydration can help you to:**

- Support your immune system
- Obtain weight goals (should you gain, lose, or maintain your weight?)
- Maintain muscles and strength to improve independence and complete your recommended therapy
- Maintain energy levels and reduce fatigue
- Lessen side effects of treatment and prevent treatment delays that can be caused by side effects
- Improve recovery time and healing

Tallahassee Memorial Cancer Center has Registered Dietitians that specialize in Oncology Nutrition are available to help you with your individual journey. They can help you decide which foods would be best for you given your current or expected issues. Request a visit with a dietitian if you have questions or concerns.

### **A dietitian can help with these topics:**

- Weight loss
- Weight gain
- Change in appetite
- Nausea / Vomiting
- Diarrhea
- Constipation
- Fatigue
- Trouble swallowing
- Sore mouth
- Sore throat
- Taste changes
- Hydration
- Supplements
- Food safety
- ...And More

As part of your comprehensive care at Tallahassee Memorial Cancer Center, Registered Dietitians are available on-site to provide you with education and support.

Ask a member of your healthcare team if you would like to meet with an oncology dietitian.



# Cancer, Sex and Sexuality

When you first learned you had cancer, you probably thought mostly of survival. But after awhile other questions may have started coming up. You may be thinking “How ‘normal’ can my life be, even if the cancer is under control?” or even “How will cancer affect my sex life?”

Sex and sexuality are important parts of everyday life. The difference between sex and sexuality is that sex is thought of as an activity—something you do with a partner. Sexuality is more about the way you feel and is linked to your need for caring, closeness and touch. Feelings about sexuality affect our zest for living, our self-image, and our relationships with others.

Keep in mind that sexual touching between you and your partner is always possible, no matter what kinds of cancer treatment you have had. This may surprise you, especially if you are feeling down or have not had sex for awhile. But it is true. The ability to feel pleasure from touching almost always remains.

You may feel uneasy talking about sex with a professional like a doctor or even with a close sex partner. Many people feel awkward and exposed when talking about sex. Even so, bring up the topic of your sex life with your doctor or another member of your health care team. You have a right to know how your treatment will affect nutrition, pain, and your ability to return to work. And you have the right to know the facts about your sex life.

## Keeping Your Sex Life Going Despite Your Cancer Treatment

Here are some points to keep in mind as you continue your sex life during or after cancer treatment:

- Learn as much as you can about the effects your cancer treatment may have on sexuality.
- Keep in mind that, no matter what kind of cancer treatment you have, you will still be able to feel pleasure from touching.
- Try to keep an open mind about ways to feel sexual pleasure.
- Try to have clear, two-way talks about sex with your partner as well as your doctor.

- Boost your self-esteem. Remind yourself about your good qualities. Eating right and exercising can help keep your body strong and your spirits up. Listen to inspiring music, look at beautiful scenery, surround yourself with affirmative friends, do what it takes to be uplifted. Practice relaxation techniques and get professional help if you think you are depressed.

## Professional Help

The first step in finding help for a sexual problem is to talk to your doctor. If your cancer specialist can't help you, ask your family doctor or other member of your health care team. If needed, ask for a referral to someone who specializes in sexual problems. Call the patient navigator at 431-ICAN (4226) to find resources. Get the help you need, sexual intimacy is an important part of life which can continue very meaningfully after a cancer diagnosis.

## Suggested Readings

- Woman Cancer Sex by Anne Katz (2009)
- Man Cancer Sex by Anne Katz (2009)
- The Lovin' Ain't Over: The Couple's Guide to Better Sex after Prostate Disease by Ralph and Barbara Alterowitz (1999)
- Intimacy After Breast Cancer: Dealing with Your Body, Relationships and Sex by Gina M. Maisano (2010)
- Gynecological Cancer Guide: Sex, Sanity and Survival by Margaret Heffernan and Michael Quinn(2003)
- Men's Health: Your Prostate Sex Gland and Cancer by Anthony Saura (1998)
- Sexual Function in the Prostate Cancer Patient by John P Mulhall (2009)
- Breast Cancer Husband: How to Help Your Wife(and Yourself) during Diagnosis, Treatment and Beyond by Marc Silver (2004)
- A Gay Man's Guide to Prostate Cancer (Journal of Gay & Lesbian Psychotherapy Monographic“Separates”) by Gerald Perlman and Jack Drescher(2005)

## Suggested Websites:

- [http://www.cancer.org/docroot/MIT/MIT\\_7\\_1x\\_SexualityforWomenandTheirPartners.asp](http://www.cancer.org/docroot/MIT/MIT_7_1x_SexualityforWomenandTheirPartners.asp)
- [http://www.cancer.org/docroot/MIT/MIT\\_7\\_1x\\_SexualityforMenandTheirPartners.asp](http://www.cancer.org/docroot/MIT/MIT_7_1x_SexualityforMenandTheirPartners.asp)
- <http://www.livestrong.org/we-can-help/fertility-services/>



# Quit Smoking

Quitting is important for anyone who smokes tobacco – even people who have smoked for many years. For people who already have cancer, quitting may reduce the chance of getting another cancer. Smoking has been linked to cancers of the lung, larynx, pharynx, esophagus, kidney, oral cavity, pancreas, bladder and cervix.

Quitting smoking is not easy, but it can be done—many millions of Americans have stopped—and it could be the most important thing you will ever do for your health. Your body begins to heal itself rapidly when you quit smoking. Levels of carbon monoxide and nicotine decline, sense of taste and smell improve, and breathing becomes easier, all within 72 hours.

## Quit Tips

Don't be discouraged if your first attempts to quit aren't successful. Many smokers have to try several times before quitting permanently.

No one approach is right for everyone. Experiment with different ones until you find the one that works for you.

- Set a quit date and stick to it. Try to choose a time where outside stresses will be minimized.
- Add walking or other exercise to your daily routine.
- Eat regular meals to keep your blood sugar even. Hunger may increase the urge to smoke.
- Avoid or limit sugar, alcohol and caffeine, which can also increase the urge to smoke.
- Drink lots of water.
- When the urge to smoke comes, breathe deeply for a few minutes.
- Put the money you would have spent on cigarettes in a jar each day you don't smoke, and use that money to buy a reward for yourself.
- Enjoy being a non-smoker.

## Ways to Get Help

Ask your doctor about medicine or nicotine replacement therapy, such as a patch, gum, lozenge, nasal spray or inhaler. Your doctor can suggest a number of treatments that help people quit.

now offers Quit Smoking Now (QSN) classes at the Tallahassee Memorial Cancer Center.

The Quit Smoking Now program is a 6 week program, designed by an ex-smoker that provides you with support, guidance and resources to help you quit. You can find the dates and times of QSN on the Cancer Center page of [www.tmh.org](http://www.tmh.org) in the Survivorship Program and Events tab. Register by calling 850-224-9340 or find another class offered in our area by calling 1-877-848-6696 or online at: <http://www.ahectobacco.com/calendar/>

It addresses the many issues related to quitting smoking, such as:

- Coping with anger, sleep problems and cravings, which are common for those who quit smoking.
- Managing stress
- How physical activity and healthy food choices can make quitting smoking easier.
- How to prevent relapse (taking up smoking again)
- What to do when you have friends and family who smoke around you
- Identifying and controlling your smoking/tobacco “triggers”

Call the Florida Quitline @ 1-877-848-6696 or go online at [floridaquitline.com](http://floridaquitline.com). The Florida Quitline was established to help those with a desire to free themselves from cigarettes, smokeless and all other forms of tobacco successfully reach their goal and offers all of its services free of charge in both English and Spanish.

Call staff at NCI's Smoking Quitline (1-877-44U-QUIT) or instant message them through Live Help (<http://www.cancer.gov/help>)

They can tell you about :

- Ways to quit smoking
- Groups that help smokers who want to quit
- NCI publications about quitting smoking
- How to take part in a study of methods to help smokers quit

Go online to [Smokefree.gov](http://www.smokefree.gov) (<http://www.smokefree.gov>) This is a federal government web site. It offers a guide to quitting smoking and a list of other resources.





# Medical Music Therapy

Medical music therapists at TMH use evidence-based music interventions in the clinical setting to enhance emotional well-being, physical abilities, and cognitive skills of TMH patients.

## Benefits for Cancer Patients

Music therapy has been shown through research to be effective at addressing both physical and psychological factors associated with cancer treatment. Specifically, medical music therapists can assist patients at TMH by:

- Improving quality of life,
- Increasing relaxation and assisting with sleep and rest,
- Enhancing mood, alleviating depression and anxiety,
- Providing counseling and assistance with coping, and
- Decreasing perception of pain

Research shows that addressing psychological factors through music therapy has the potential to affect physical symptoms associated with the treatment of cancer.

## Ways to use Music to Enhance Wellness

The following are ways in which anyone can incorporate music into their daily life to help enhance general well-being:

- Making music for stress relief/enjoyment
- Music-listening to assist with relaxation
- Music-assisted exercise

Medical music therapists are available to consult with TMH patients on these techniques and other ways to use music to improve wellness.

## How to Contact a Medical Music Therapist

Medical music therapists at TMH are available from 9:00 am to 5:00 pm, Monday through Friday, and at other times by appointment. To contact a medical music therapist, please call 431-7468.

## Music Therapy Resources

The medical music therapy program at TMH is the result of collaboration with the Florida State University College of Music. Find out more about the program at:

<http://musictherapy.fsu.edu/tmh/>

The American Music Therapy Association website provides information about the music therapy profession and how to find a music therapist:

[www.amta.org](http://www.amta.org)

## Patient Comments

Below are patient's comments about the medical music therapy program at TMH:

"This was a super experience for me. Had I known you had music therapy, I would have asked daily. Very uplifting. The music was great. I liked each second. Thank you so very much for sending a music therapist my way. My spirit was lifted high..."

"It really helped take my mind off the pain in my legs, being way from my family, and the loss of my friend I had in my accident..."

"Music therapy really brought smiles to our faces and also brightened our day. Thank you very much for your services..."

"The music therapist was very inspiring, not only in her singing and playing, but also in her words of comfort..."

"You're great! It was very uplifting and enjoyable..."

"The music therapist remembered my husband's request from a previous visit, learned the songs, and played them at the subsequent visit- very impressive! The staff seems to appreciate the music, too. Creates a positive environment. Thank you..."



# Integrative Services

Mind, Body and Spirit services are recognized, embedded, and integrated into the overall care of our patients and families. These include such services as:

- Spiritual Care
- Music Therapy
- Art Therapy
- Animal Therapy
- Yoga
- Nutrition/Dietary Consultations

To access the services and resources, please call 850.431.ICAN (4226) or submit your request to one of your healthcare providers.



# Community Cancer Support

## **Tallahassee Memorial Cancer Center: Cancer Wellness & Support Group for Individuals & Caregivers**

Meets the 2nd and 4th Thursday of each month at Tallahassee Memorial Cancer Center, 5:30-7 p.m. 850-431-4226 (press 5 for a Patient Navigator)

## **Tobacco Free Florida - Quit Your Way - Group Quit**

Group Quit is the in-person option of Tobacco Free Florida Quit Your Way services and is open to the general public. Free nicotine replacement patches, gum, and lozenges available (while supplies last and if medically appropriate). Call 850-224-9340 for current schedule.

## **Ukulele Choir**

Our Music Therapist will lead this group session. No prior music experience is needed, beginners are welcome and encouraged to attend. Ukulele's are provided to use during group sessions. Meetings will occur on the 1st and 3rd Thursday of the month, please contact 850-431-7468 for meeting time.

## **Tallahassee Memorial: A Women's Place**

Prosthesis and Bra fittings. Contact: 850-431-4928

## **FORCE**

Do you have a BRCA mutation or another gene mutation associated with increased breast and/or ovarian cancer risk? Here's your chance to meet others who know what you're going through, to ask questions, learn or just listen in a safe and supportive environment. You are not alone. Join us and live your life empowered! Contact Katie Farmer at [katie.farmer@tmh.org](mailto:katie.farmer@tmh.org) or 850-431-4041

## **Chicken Soup**

A 40+ women's support group of breast cancer survivors and newly diagnosed women. Meets the 1st Wednesday of the month at New Bethel AME Church in Quincy. Contact Catherine Moore before attending @ 850-627-7818

## **Sisters Alive/Soul Survivors**

All women's support and educational group. Meets the 2nd Saturday of every month at 9:00 am at the American Cancer Society Leon Unit. Contact Harriette Hudson, 850-656-2512

## **Ovarian Cancer Survivors Group**

Caring and support for survivors, families, and friends. Meets the 2nd Monday of every month at 5:30 pm at the Tallahassee Memorial's Cancer Center. Contact: Kathy Neill, 850-322-5897

## **The Leukemia & Lymphoma Society**

An agency offering support, education, advocacy, and financial assistance for cancer patients. Contact: Maria Avenancio, 800-785-0733

## **Better Breathers**

Men and women survivors of and/or living with lung ailments. Meets the 1st Tuesday of the month at 1:00 pm at Capital Regional Educational Room. Contact: Patty Ballantine, 850-386-2065 ext. 1141

## **Lee's Place**

A grief and loss counseling center for children, adults, groups, and families. Contact: Brenda Robalais, 850-841-7733

## **Wakulla County Cancer Support Group**

Meets to discuss individual concerns and life-style guidelines for the prevention of cancer. Meets the 3rd Thursday of each month at 7:00 pm at the Crawfordville United Methodist Church. Contact: Marge Kinder, 850-926-6050

## **Caregiver Support Group**

Support group for anyone caring for a loved one with a chronic illness. Meetings are held the 2nd Friday of every month at Broadview Assisted Living. Contact: 850-431-5037

## **Multiple Myeloma Support Group**

Support for patients, caregivers, family members and friends who have been affected by multiple myeloma. Meets the 4th Monday of every month from 5:30 to 7:30 pm at Westminster Oaks Campus in the Pool Clubhouse. Contact: Julia Pallentino, 850-933-7274 or [arnpplaw@comcast.net](mailto:arnpplaw@comcast.net)

**Reach to Recovery**

American Cancer Society program for breast cancer survivors.

Contact: 1-800-ACS-2345

**Look Good, Feel Better**

American Cancer Society program where women undergoing cancer treatment can learn make-up and hair techniques from a licensed, trained cosmetologist. Lunch is provided, free of charge, at each session. Held every other month at Tallahassee Memorial Cancer Center.

Contact: 1-800-227-2345

**I Can Cope**

American Cancer Society program that offers Educational classes online that provides reliable information, peer support, and practical coping skills. Available for patients, family and friends. Go to [www.cancer.org](http://www.cancer.org) or 1-800-ACS-2345 for more info.

# Cancer Resources

The following pages include a list of Web sites and other resources that can help you in your search for information.

**Adjuvant Therapy.com:** Information about therapy choices. [www.adjuvantonline.com](http://www.adjuvantonline.com)

**American Institute for Cancer Research (AICR):** The AICR fosters research on diet, physical activity, and cancer prevention, and is a good site for information about nutrition. <http://www.aicr.org>

**American Cancer Society:** Cancer information covering medical information, treatment decision tools, news updates, and support resources. [www.cancer.org](http://www.cancer.org) 1-800-ACS-2345

**American Lung Association:** <http://lungusa.org>

**American Society of Clinical Oncology:** Has goals of improving cancer care and prevention and ensuring that all patients with cancer receive the highest quality care. [www.asco.org](http://www.asco.org) 1-703-299-0150.

**American Society of Plastic and Reconstructive Surgeons:** To advance quality care to plastic surgery patients by encouraging high standards of training, ethics, physician practice and research in plastic surgery. [www.plasticsurgery.org](http://www.plasticsurgery.org)

**Asian American Network for Cancer Awareness, research and Training:** Cancer information in Asian languages. [www.aancart.org](http://www.aancart.org)

**Breast Cancer.Net:** Features articles about treatment and support. [www.breastcancer.net](http://www.breastcancer.net)

**CancerCare:** Provides free, professional support services to anyone affected by cancer. Services include counseling, education, financial assistance and practical help. [www.cancercare.org](http://www.cancercare.org) 1-800-813-HOPE.

**CancerCare Linking A.R.M.S.:** Offers qualified low-income, under-insured or uninsured people diagnosed with breast cancer financial assistance grants to cover the costs of oral chemotherapy and hormonal therapy medications, pain and anti-nausea medication, lymphedema supplies and medical equipment through a partnership with Susan G. Komen for the Cure®. [www.cancercare.org](http://www.cancercare.org) 1-800-813-HOPE.

**Cancer Hope Network:** Matching patients and/or family members with trained volunteers Throughout the US who have recovered from similar cancer experiences. [www.cancerhopenetwork.org](http://www.cancerhopenetwork.org)

**CancerNet:** National Cancer Institute site with treatment information, clinical trials, research and literature. <http://cancernet.nci.nih.gov/cancertopics/types>

**Cancer Portfolio:** Collaborative site of UK and US researchers. [www.cancerportfolio.org](http://www.cancerportfolio.org)

**Cancer Control and Research Advisory Council-**  
<http://www.moffitt.usf.edu.ccrab>

**Cancer Information Services:**  
<http://cis.nci.nih.gov>

**Cancer Survivor Network:** Offshoot of American Cancer Society specific to issues of people who have cancer. [www.ascsn.org](http://www.ascsn.org)

**CaringBridge.org:** provides free website to connect people experiencing a significant health challenge to family and friends. [www.caringbridge.org](http://www.caringbridge.org)

**Celebrating Life:** Site for African American women with breast cancer. [www.celebratelife.org](http://www.celebratelife.org)

**Centers for Disease Control and Prevention, Comprehensive Cancer Prevention and Control-**  
<http://www.cdc.gov/cancer/index.htm>

**CenterWatch Clinical Trials Listing Service-** Provides information on clinical trials and specific studies currently being conducted. [www.centerwatch.com](http://www.centerwatch.com)

**Colorectal Cancer Information Links-**  
<http://www.cdc.gov/cancer/linksalt.htm#colorectal>

**ConnieCaps, Inc.** Founder Linda Blakely provides stylish, handcrafted hats free of charge to cancer patients who have lost their hair. Visit [www.conniecaps.org](http://www.conniecaps.org), and reference referral number TMH-7105.

**Corporate Angel Network:** Provides air transportation to treatment centers. [www.corpangelnetwork.org](http://www.corpangelnetwork.org) 1-866-328-1313

**Cure Breast Cancer:** News, treatment information, patient stories. [www.curebreastcancer.org](http://www.curebreastcancer.org)

**CURE Magazine:** Free magazine for cancer patients, survivors, and caregivers [www.curetoday.com/subscribe](http://www.curetoday.com/subscribe) 800-210-CURE

**Facing Our Risk of Cancer Empowered, Inc. (FORCE):** provides information for women whose family history or genetic status puts them at high risk of ovarian and/or breast cancer. [www.facingourrisk.org](http://www.facingourrisk.org) 1-866-824-7475

**Fertile Hope:** provides reproductive information, support and hope to cancer patients whose treatments present the risk of infertility. [www.fertilehope.org](http://www.fertilehope.org) 1-888-994-HOPE.

**Fertile Action:** Specifically, we Educate, Advocate, Support and Provide Financial Aid to women touched by cancer. Fertile Action promises to protect every woman's vision of her future as a mother. [www.fertileaction.org](http://www.fertileaction.org)

**Florida Cancer Clinical Trials Cooperative, Inc. (FCCTC):** <http://www.floridacancertrials.com>

**Gilda's Club:** Promises meeting places where men, women and children living with cancer, along with their families and friends, can join with others to build a network of social and emotional support. [www.cancercare.org](http://www.cancercare.org) or 1-800-GILDA-4-U.

**Gillette Cancer Connection:** Good site for newly diagnosed women. Information for partners and family members as well. [www.gillettecancerconnect.org/women](http://www.gillettecancerconnect.org/women)

**Hope for Two...**The Pregnant with Cancer Network. Resource providing pregnant women diagnosed with cancer information, support and hope. <http://hopefortwo.org>

**Inflammatory Breast Cancer Research Foundation:** dedicated to researching the causes of Inflammatory Breast Cancer (IBC), an advanced and accelerated form of breast cancer usually not detected by mammograms or ultrasounds. [www.ibcresearch.org](http://www.ibcresearch.org) 1-877-786-7422

**John Nick Foundation:** Information on male breast cancer. [www.johnwnickfoundation.org/malebreastcancer.html](http://www.johnwnickfoundation.org/malebreastcancer.html)

**Kids Connected:** Provides friendship, understanding, education and support for kids and teens who have a parent with cancer or have lost a parent with cancer. [www.kidsconnected.org](http://www.kidsconnected.org) or 1-800-899-2866.

**Living Beyond Breast Cancer:** Newsletter, information on quality of life. [www.lbbc.org/default.html](http://www.lbbc.org/default.html)

**Lots of Helping Hands:** online caring Communities that help restore health and balance to caregivers' lives. Our service brings together caregivers and volunteers through online Communities that organize daily life during times of medical crisis or caregiver exhaustion. Caregivers benefit from the gifts of much needed help, emotional support, and peace of mind, while volunteers find meaning in giving back to those in need. <http://lotsahelpinghands.com/>

**Mautner Project, The National Lesbian Health Organization:** provides education, support and other services to lesbians with cancer. [www.mautnerproject.org](http://www.mautnerproject.org) 1-866-MAUTNER

**Max Foundation:** Dedicated to improving quality of life and survival rates of patients with blood related cancers. [www.themaxfoundation.org](http://www.themaxfoundation.org) 1-888-462-9368

**MD Anderson Cancer Center:** Up to date information and news on cancer. [www.mdanderson.org](http://www.mdanderson.org)

**Medline Plus:** Health information from the Library of Medicine and National Institute of Health. [www.medlineplus.gov](http://www.medlineplus.gov)

**Memorial Sloan Kettering Medical Center:** [www.mskcc.org](http://www.mskcc.org)

**Moffitt Cancer Answers:** Free cancer information service. Staffed by experienced registered nurses who can provide information related to cancer. 1-888-MOFFITT (663-3488)

**National Breast Cancer Coalition:** Grassroots organization with a mission to eradicate breast cancer through action and advocacy. [www.stopbreastcancer.org](http://www.stopbreastcancer.org) 1-800-622-2838

**National Comprehensive cancer Network:** treatment guidelines, supportive care [www.nccn.org/patients/patient\\_gls.asp](http://www.nccn.org/patients/patient_gls.asp)

**National Cancer Institute:** Treatment information, literature, statistics. <http://www.nci.nih.gov>



**National Cancer Institute Cancer Fact sheets:** provides an index of all the National Cancer Institute Cancer Fact Sheets. [www.cancer.gov/cancertopics/factsheet](http://www.cancer.gov/cancertopics/factsheet)

**National Cancer Institute's Cancer Information Service:** provides information and resources to patients, the public and health care providers. [www.cancer.gov](http://www.cancer.gov) 1-888-644-6226.

**National Center for Complimentary and Alternative Medicine at the National Institute of Health:** provides information on complimentary and alternative health care. [www.nccam.nih.gov](http://www.nccam.nih.gov) 1-888-644-6226

**National Lymphedema Network:** [www.lymphnet.org](http://www.lymphnet.org) 1-800-541-3259

**National Marrow Donor Program:** Helps people who need life-saving marrow or blood cell transplants. Offers transplant support, unit matching, education, resources, and financial assistance. [www.marrow.org/patient](http://www.marrow.org/patient) 1-888-999-6743

**National Patient Air Travel HELPLINE:** provides air transportation to treatment centers. [www.patienttravel.org](http://www.patienttravel.org) 1-800-296-1217.

**National Women's Health Information Center:** <http://www.4women.gov>

**Oncology Nursing Society:** Patient and family information. [www.ons.org/patientEd](http://www.ons.org/patientEd)

**Ovarian Cancer Information Links:** <http://www.cdc.gov/cancer/linksalt.htm#ovarian>

**Partnership for Prescription Assistance:** Provides information on how to find pharmaceutical manufacturer assistance programs. [www.pparx.org](http://www.pparx.org) 1-888-512-3861.

**Patient Advocate Foundation:** Provides legal and advocacy help with disputing insurance claim denials and offers co-pay relief program that provides financial assistance to eligible patients who are being treated for breast cancer. [www.patientadvocate.org](http://www.patientadvocate.org) 1-800-532-5274.

**Prostate Cancer Information Links:** <http://www.cdc.gov/cancer/linksalt.htm#prostate>

**Sisters Network, Inc.:** provides outreach and education on the impact of breast cancer in the African American community. [www.sistersnetworkinc.org](http://www.sistersnetworkinc.org) 1-713-781-0255

**Skin Cancer Information Links:** <http://www.cdc.gov/cancer/linksalt.htm#skin>

**Susan G. Komen Foundation:** Promises to save lives and end breast cancer forever by empowering people, ensuring quality care for all and energizing science to find the cures. [www.komen.org](http://www.komen.org) 1-877-GO KOMEN (1-877-465-6636).

**Tallahassee Memorial HealthCare-A Woman's Place:** Local shop for bras/prosthesis or partial breast prosthesis after lumpectomy. Also can be measured for lymphedema garments. 850-431-4926.

**Y-me:** information and support, founded by breast cancer patients. [www.y-me.org](http://www.y-me.org)

**YWCA:** Offers ENCOREplus® breast and cervical cancer program that provides outreach, education and screening mammograms to women who are most in need and lack access to breast health services. [www.ywca.org](http://www.ywca.org) 1-202-467-0801.

The information provided in this section will help you plan and prepare for your treatment. However, it is not meant to replace the individual attention, advice, and treatment plan of your oncologist and medical team.











# ***My Finances / Insurance***





# My Finances and Insurance

## **If you have health insurance:**

Always bring your health insurance card to every doctor or medical visit.

Notify your insurance company according to their guidelines. For most policies, you must call to pre-certify any inpatient hospital admission. Some require an authorization for any service costing over a set amount, such as \$500. Knowing your policy's guidelines and making that phone call will save you money and hassle.

Health insurance is like house or car insurance in that different policies cover different types of benefits. It is important to fully understand what your policy covers.

Be aware that some health plans may not pay for some special medical consultations. Other plans may pay for them, but you may have a higher co-pay than for a regular visit. If you have any questions, call your insurance company. Try to talk with the same person each time you call if possible.

Do not let your health insurance policy expire. New insurance may be difficult to obtain while you are in treatment. Pay premiums in full and mail them in plenty of time to arrive and be processed before the due date. Some policies have a grace period for late payments; however, if you require care during the grace period, any late payments may complicate authorizations.

Call your employee benefits administrator to request a copy of your complete insurance policy. Ask for the entire detailed benefit description, usually called a "Summary Plan Description," not a brief overview or informational brochure. This document may have a number of pages, and your employer will give you a copy upon request.

Put aside some time to review your health policy line-by-line, and highlight relevant sections. Closely read any sections on exclusions and exceptions.

Understand the dollar amount of your policy's "out-of-pocket maximum." If you have questions, ask your employee benefits administrator for clarification. Find out how to call a "claims assistant" at your insurance company. These people can help you with accurate information if

you have questions about coverage or a specific claim.

If you have a hard time sorting out what has been paid and what has been applied to your deductible, call your insurance company's claims assistant and ask that a "Claims Summary" be mailed to you. This should list dates of service, billed amounts, how much was applied to your deductible, and how much your insurance company paid.

Try to establish a warm human connection when you call to talk with a claims assistant. "Thanks so much for your help," will get you further than "I'm so frustrated with this whole thing I could scream."

"Explanation of Benefits" (EOB) letters need special attention. Never throw them away. They include important information. An EOB may indicate a payment, a partial payment or a claim denial.

When you receive an "Explanation of Benefits" (EOB), carefully read every line including all footnotes. Also, read any printing on the back of the EOB. Watch for language such as, "Please contact your provider to resubmit the claim with a valid diagnostic code. If this information is not received within 90 days of your receipt of this request, please consider this claim denied." Be sure to meet these stated guidelines on time.

"Pre-authorization" letters also need special attention. Watch for language such as, "This authorization does not guarantee payment." Call your insurance company if you have any questions.

Dealing with insurance matters can be frustrating. Take things one step at a time. Take a break. Ask for help if you need it.

If you phone your insurance company for any reason, enter each telephone call into this Insurance Tracking form.

Write down the name, title and phone number of anyone you speak with. Note what was discussed, mailed or promised.

This will help you remember the details of each call.

### **Setting up a system to manage paperwork:**

Identify a small work area and stock it with a stapler, yellow highlighter, pens, stamps, blank insurance claim forms and file folders. Setting up this space can be a good job for a friend who wants to help.

Remember to document, document, and document. Create a “paper trail” to keep a record of telephone and mail contacts. The tracking forms at the end of this section will help.

Be aware that you will receive a variety of mail, such as insurance pre-authorization notifications, authorizations and bills from various sources.

A strategy some people find useful is to put a basket by the front door for all treatment-related envelopes. Then schedule an hour or so once a week to sit down and open each envelope. Read the material line-by-line and use your highlighter to note important information. This may be a task you can turn over to a family member or good friend.

As insurance “Explanation of Benefits” (EOB) forms arrive, attach the EOB to its related claim form, the original bill and any record of your own payments.

Write the claim number and policy number on every document. Include the procedure code if one is given.

If you are required to fill out a form and return it, always make a copy for your file.

If the document is especially important and has a deadline hand-carry it to the post office and pay for delivery tracking, such as certified mail with the green “return receipt requested” post card or a computer-based “Delivery Confirmation” with a tracking number.

Submit claims for all medical expenses even if you are not sure if a particular expense is covered.

### **What to do if an insurance claim is denied:**

If a person has health insurance and a particular claim is denied, you can take the following steps to resolve the problem:

In all interactions with the insurance company about a claim, keep copies of all correspondence and note the claim number and policy or procedure code on all correspondence. Also note the name of any customer service or claims representative spoken with on the telephone.

Call the insurance company to find out why the claim was denied. If it is still unclear, study the explanation of benefits form. In some cases, the denial may be the result of a claim being improperly documented, such as a particular service being inadvertently omitted.

Check the facts. Review the policy to make sure that pre-certification, authorization and other procedures required by the insurer were followed. For example, claims for prosthetic bras, implants and wigs require a copy of both the prescription and the bill.

Enlist a doctor’s help if fees, charges or procedures are questioned. Most physicians and their staff are experienced in working with insurance companies and can help answer questions. Ask the physician to write a letter to the insurance company documenting and/or justifying the charges, and be sure to keep a copy.

If the claim is denied because the insurance company states that a particular treatment is experimental or under investigation, enlist a physician to provide assistance. If he/she can give the insurance company evidence that the scientific literature supports the use of a particular therapy for a particular patient, then the procedure cannot technically be labeled as experimental. To accomplish this, ask the doctor to help obtain peer review study reports and support letters from other oncologists performing the same procedure. National patient support organizations can also help.

Ask for a formal review of the denied claim. Often, claims that were denied initially are paid in subsequent reviews. If this fails, ask for an appeal of the review using outside oncology experts to review the medical records and claim.

If these steps fail to yield reimbursement for a claim that a patient and her physicians believe is justified, a final recourse would be to contact a lawyer. National patient support organizations can help identify lawyers in each state who specialize in cancer-related insurance issues. Information courtesy of the Susan G. Komen Breast Cancer Foundation, [www.komen.org](http://www.komen.org) or 1-800- I’M AWARE® (1-800-462-9273)

### **Taxes**

Medical costs that are not covered by insurance policies can sometimes be deductible. Tax-deductible expenses might include mileage for trips to and from medical appointments; out-of-pocket costs for treatment, prescription drugs or

equipment; and the cost of meals during lengthy medical visits away from home.

Obtain publications related to medical deductions from the Internal Revenue Service and from the state where you file your taxes. Find out if there are special rules for people who are self-employed, have a business or domestic partner, or other special situations.

Publications are mailed free upon request and usually arrive within two or three weeks. You can also view them online and print them.

Internal Revenue Service publications are available by phone at 1-800-829-1040 or online at [www.irs.ustreas.gov](http://www.irs.ustreas.gov).

If you use a tax advisor or financial planner, consult with that person after your diagnosis.

The “Expense Tracking” form at the end of this section can be used to help document out-of-pocket expenses as you go.

### **COBRA (Consolidated Omnibus Budget Reconciliation Act)**

If you have a group health insurance plan through an employer with 20 or more employees, this federal legislation may enable you to keep your group coverage plan in the event of job loss, reduction in work hours, transition between jobs and certain other cases. Coverage may be available for 18 months. Qualified individuals are required to pay the entire premium cost that the employer had been paying, plus a few percent. This may be quite expensive, yet is still less costly than obtaining individual insurance outside of a group plan.

Rules for COBRA are complex. Ask your employer for written information. You can obtain further information and a fact sheet from the U.S. Department of Labor Employee Benefits Security Administration. Call 415-975-4600 or visit [www.dol.gov/dol/topic/health-plans/cobra.htm](http://www.dol.gov/dol/topic/health-plans/cobra.htm).

### **Under the Paid Family Leave Act,**

disability compensation may be extended to cover individuals who take time off of work to care for a seriously ill spouse, parent, domestic partner or other reasons. The Paid Family Leave insurance program, also known as the Family Temporary Disability Insurance program, is administered by the State Disability Insurance (SDI) program. An estimated 13 million California workers covered by the SDI program are also covered for Paid Family Leave insurance benefits. The rules are complex, so check into whether you have job protection or

return rights, whether benefits are taxable, and other issues.

### **Disability Benefits 101**

([www.disabilitybenefits101.org](http://www.disabilitybenefits101.org)) is a knowledgeable source if you need more help understanding your benefits.

This comprehensive website offers information on disability benefits, State Disability insurance, health insurance, Medi-Cal, Medicare, COBRA and a variety of additional programs administered by state, federal and private organizations. The organization’s purpose “is to take a broad, customer-centered view, focusing on the linkages among programs” and how programs interact with each other, discussing them “under one roof, in plain language.”

### **The Americans with Disabilities Act**

The Americans with Disabilities Act (ADA), enforced by the Equal Employment Opportunities Commission (EEOC), prohibits all discrimination related to a disability, a perceived disability, and a history of disability. Employers must make reasonable accommodations in the workplace for qualified individuals with a disability. They are required to treat all employees fairly and equally and cannot ask employees personal questions other than job-related medical questions. The ADA also protects an employee whose family member has a disability.

### **The Family and Medical Leave Act of 1993**

The Family and Medical Leave Act (FMLA) protects employees when they take leave because they are ill or are caring for a spouse, child, or parent who is ill. Through the FMLA, employees receive:

- A total of 12 weeks unpaid leave
- Continued benefits during leave
- The option to use vacation and sick leave during medical or family leave

The FMLA has specific requirements. For example, the employer must have more than 50 employees. And an employer does not have to hold a position open if an employee uses more than 12 weeks of leave in a year. Because states and districts operate differently, contact your local attorney general’s office or an employment lawyer for more information.

The Job Accommodation Network provides free information about the ADA and the employability of people with disabilities.

### **If you begin to feel overwhelmed about finances:**

Even in the best of healthy times, money is a difficult area for many of us. In our culture, personal money issues are not usually discussed openly with friends or family. We may feel that we are supposed to “make it” on our own and never ask for help.

To need help is simply part of being human. Break the silence. Ask for assistance. Take action in small but steady steps.

Hospitals and physician offices usually have employees who specialize in insurance claims, reimbursement and public benefits. They may be called financial counselors, case managers or financial assistance planners. Hospital social workers may be able to suggest financial options and can offer emotional support as well.

Seek assistance from a community volunteer, an advocacy organization, a family member or friend.

Taking Charge of Money Matters is a workshop developed by the American Cancer Society and the National Endowment for Financial Education. This two hour workshop addresses money issues that arise during or after a person’s cancer treatment. Specially trained and experienced facilitators lead the workshop. Guest speakers may include insurance specialists, Social Security/Medicare/Medicaid representatives, licensed certified financial planners, hospital billing representatives, attorneys and others. To find out if Taking Charge of Money Matters is available in your community or by telephone conference, call 1-800-ACS-2345. You may want to have someone attend with you or go in your place depending on how you are feeling.

### **Getting the most from a service:**

#### **What to ask-**

No matter what type of help you are looking for, the only way to find resources to fit your needs is to ask the right questions. When you are calling an organization for information, it is important to think about what questions you are going to ask before you call. Many people find it helpful to write out their questions in advance and take notes during the call. Another good tip is to ask the name of the person with whom you are speaking in case you have follow-up questions. Below are some questions you may want to consider when calling or visiting a new agency to learn how they can help you:

- How do I apply for your services?
- Are there eligibility requirements? What are they?
- Is there an application process? How long will it take? What information will I need to complete the application process? Will I need anything else to get the service?
- Do you have any other suggestions or ideas about where I can find help?

The most important thing to remember is that you need to be willing to ask for help to receive

it. Asking can be the hardest part of getting help. Cancer is a very difficult diagnosis and disease, but there are people and services that can ease your burdens and help you focus on your treatment and recovery.

The information on “Getting the Most from a Service” was adapted with permission from CancerCare, a national nonprofit organization that provides free professional support services for people with cancer and their families. Find out more about CancerCare by calling 1-800-813-HOPE (4673) or visiting [www.cancercare.org](http://www.cancercare.org).

#### **Tips for Organizing Financial Information**

Approved by the Cancer.Net Editorial Board, 06/2015

After a cancer diagnosis, many people find that becoming well organized helps them gain a sense of control over all the information they receive, including finances. The following suggestions may help as you start to track your costs and set up a personal system of organization.

Create a filing system that works for you. Find information quickly and easily by using a filing cabinet or simple desktop divider with individual folders. This system also helps keep important information in one place. File new information as soon as possible, so it doesn't get misplaced. Your files may include:

- Notes made during doctors' appointments
- Copies of your laboratory test results
- Your insurance information
- Contact information for your doctor's office, medical center, insurance company, support organizations, and others
- Bills
- Explanations of benefits (EOB) materials that describe what benefits your health insurance paid for each service
- Receipts for health care expenses

Use technology as an organizational tool. Some people prefer to use a computer to keep track of important information. Creating a spreadsheet with columns for the appointment date, doctor's name, amount paid, status of the insurance claim, and other important notes can help you quickly see the status of payments for medical services. It is also possible to track financial information related to your cancer care online or using an app.

Request a case manager. Ask your health insurance company if you can have a case manager. This way you can talk with the same person each time you need to call. Keep current copies of all insurance policies and refer to them by name and number in any communications about insurance coverage.

Take good notes. Maintain a written record of all conversations you have with an insurance company representative, including the date, name of the person you spoke with, and what was said. Put the newest records at the front of your file so you have a clear and up-to-date list of these discussions.

Keep track of all unreimbursed medical expenses. This information may include the dates of each service, the amount paid, and the name of the provider. You may be able to claim these expenses for tax purposes. (A tax professional can provide advice on current rules and eligible expenses.)

Plan for changes in income and expenses. Try to decide ahead of time how to adjust your budget to deal with any loss of income because of less time at work or expenses not covered by insurance.

Ask for help. A trusted friend or family member is a great resource if you need help keeping track of your regular monthly bills. You might also want to consider using a bill-paying service to ensure payments are made on time.

### **Additional Resources for Financial Assistance**

Financial Assistance Programs for Chemotherapy Medications and Treatments

A social worker is available for consultation during your cancer care at Tallahassee Memorial HealthCare. Talk with your doctor and nurses to request a referral to meet with the Oncology Social Worker. Here are some of the ways a social worker may be able to assist patients while receiving cancer treatment:

1. Transportation issues
2. Financial assistance
3. Insurance issues
4. Medication assistance
5. American Cancer Society and other community resource referrals
6. Assist with obtaining durable medical equipment for patients use at home as needed.
7. Arrange home healthcare services for patients as needed.

### **American Cancer Society 1-800-227-2345**

24 hours, seven days a week - cancer information, support and community resources. [www.cancer.org](http://www.cancer.org)

This respected organization offers a range of information, resources and publications. Local units provide practical and emotional services for cancer patients, including transportation to and from medical appointments, support services, and wigs and head coverings for women in treatment. Staff can accept calls in Spanish and distribute most publications in Spanish.

## **Costs Related to Clinical Trials**

### **National Cancer Institute**

<https://www.cancer.gov/about-cancer/treatment/clinical-trials>

Some states require health plans to cover patient care costs in clinical trials. For more information, see the National Cancer Institute's information at the web site address listed above.

## **General Financial Assistance Information**

### **Abbott Patient Assistance Foundation**

Provides medical nutrition products (Glucerna, Jevity, Ensure, Juven) to individuals who cannot afford to purchase Abbott products.

1-800-222-6885, option 5

### **Brenda Mehling Cancer Fund**

Provides financial assistance for patients ages 18-40 who are going through treatment. Grants are awarded to cover a variety of expenses. Please email organization through [www.bmcf.net](http://www.bmcf.net)

### **Capital Area Community Action Agency**

The CACAA is a government funded agency that provides rent and utility assistance. Call to set up an appointment. May only request assistance once a year.

850-222-2043; 309 Office Plaza Dr, Tallahassee

### **Catholic Charities**

Rent and mortgage assistance. Must call M-F, 9am-11am.

850-222-2180; 855 W. Carolina St, Tallahassee  
[www.ccnwfl.org](http://www.ccnwfl.org)

**Department of Social Service** This agency of your local county sometimes has emergency funds for rent, food, utilities, prescription drugs and medical expenses for those who are not eligible for other programs. Transportation services may be offered or mileage reimbursed. Funds are often limited. Information can be obtained by contacting your state or local Department of Social Services. Check your local telephone directory for their phone number.

### **Financial Planning Association**

Connects people with certified financial planners, based on specific needs of client.

1-800-322-4237 [www.fpanet.org](http://www.fpanet.org)

**Fundraising** Some patients find that friends, family and community members are willing to

contribute financially if they are aware of a difficult situation. Contact your local library for information about how to organize fundraising efforts.

### **Healthwell Foundation**

Provides financial support to patients diagnosed with chemotherapy-induced anemia and neutropenia, breast cancer, carcinoid tumors, colon cancer, glioblastoma, head and neck cancer, and non-Hodgkins lymphoma. Please contact organization for updated list of covered conditions.

1-800-675-8416 [www.healthwellfoundation.org](http://www.healthwellfoundation.org)

**Leukemia & Lymphoma Society** Information specialists provide accurate, up-to-date disease and treatment information. Available Monday through Friday from 9 a.m. to 6 p.m. ET. Callers may request the services of a language interpreter.

Toll-Free: (800) 955-4572 [www.lls.org](http://www.lls.org)

### **Lifeline and Link-Up Florida**

Public assistance programs that provide reductions in cost for monthly telephone bills and telephone installation fees. Call to determine eligibility. 1-800-540-7039 [www.floridaopc.gov/Pages/Lifeline.aspx](http://www.floridaopc.gov/Pages/Lifeline.aspx)

### **Low Income Home Energy Assistance Program**

For people with difficulty paying for utilities.

850-222-2043 [www.liheap.org](http://www.liheap.org)

### **Lymphoma Research Foundation (LRF)**

Provides support and education for lymphoma patients and families.

1-800-235-6848 [www.lymphoma.org](http://www.lymphoma.org)

### **Medicare**

Medicare is a federally-funded health insurance program that covers most Americans over age 65 and some people with disabilities. It provides for basic health coverage although not for all medical expenses. Co-payments and deductibles may be required. Basic benefits are determined by Congress and are the same across the country. Private supplemental insurance "Medigap" policies increase the range of coverage. Contact Medicare for information on eligibility, explanations of coverage and related publications.

Call 1-800-633-4227. [www.medicare.gov](http://www.medicare.gov)

(Some publications are available in Spanish and Spanish-speaking staff is available.)

**National Leukemia Research Association**

Provides financial assistance to leukemia patients of all ages for x-ray therapy, chemotherapy, leukemia drugs; and leukemia laboratory fees.

1-516-222-1944 [www.childrensleukemia.org](http://www.childrensleukemia.org)

**National Transplant Assistance Fund**

Provides fundraising assistance to cancer patients in need of transplants. Also provides limited financial assistance.

1-800-642-8399 [www.transplantfund.org](http://www.transplantfund.org)

**Patient Assistance Program**

A subsidiary of the Patient Advocate Foundation (see entry under "Insurance Advocacy") providing financial assistance to patients who meet certain qualifications. May help pay for prescriptions and/or treatments. Helps patients who have insurance including Medicare and Medi-Cal. This assistance lets patients who have chronic, life threatening and/or debilitating illnesses afford the out-of-pocket costs that their insurance companies require. Telephone counselors screen for eligibility. Once eligibility has been determined, a comprehensive application is processed. Patients are assigned their own call counselor who will be available to answer questions. Once the individual is approved for the program and depending on the level of need, payments may be made to the doctor, to the pharmacy or to the patient directly.

1-866-512-3861 email: [pap@patientadvocate.org](mailto:pap@patientadvocate.org)

**Sarcoma Alliance**

Hand in Hand sarcoma alliance offers financial assistance for second opinion consultations by reimbursing expenses related to travel, phone bills, costs of evaluation, and related expenses.

1-415-381-7236 [www.sarcomaalliance.org](http://www.sarcomaalliance.org)

**Insurance Assistance****Center for Medicare & Medicaid Advocacy, Inc.**

Provides advocacy and legal assistance to help the elderly and people with disabilities obtain Medicare and necessary health care.

1-860-456-7790 [www.medicareadvocacy.org](http://www.medicareadvocacy.org)

**Adrema**

Contracted through TMH. Helps TMH patients with an active account apply for disability or Medicaid.

850-431-5220

**Programs of Assistance at Hospitals**

Some hospitals have programs through which uninsured and low-income patients may qualify for assistance with their hospital expenses. Ask to speak with a hospital financial counselor or social worker about application procedures.

**Social Security Administration**

Takes applications for Medicare, Social Security Insurance (SSI) and Social Security Disability Insurance (SSDI). Apply with Social Security if your doctor feels that your disability will last one year or more. Applications can take three to four months for processing.

1-800-772-1213 <https://www.ssa.gov/applyforbenefits>

**United Way**

This national organization's information service can refer you to an agency that may provide financial help for rent, food and other basic necessities. To find the United Way serving your community, visit their web site (listed above) or check the white pages of your local telephone book. [www.unitedway.org](http://www.unitedway.org)

**Veteran's Administration**

Eligible veterans and their families may receive cancer treatment at a Veteran's Administration Medical Center. Some publications are available in Spanish, and Spanish-speaking staff is available in some offices.

1-877-222-8387 [www.va.gov](http://www.va.gov)

**Patient Advocate Foundation**

Provides education, legal counseling, and referrals for cancer patients and survivors Professional case managers and attorneys specialized in mediation, negotiation and education will advocate on behalf of patients. [www.patientadvocate.org/help.php](http://www.patientadvocate.org/help.php) concerning managed care, insurance, financial issues, job discrimination and debt crisis matters.

1-800-532-5274

**Pharmaceutical Financial Assistance Information****.Capital Area Community Action Agency**

Prescription assistance. Call or stop by between 8:00am and 10:00am with ID and copy of prescription(s).

301 Office Plaza Dr, Tallahassee

850-222-2180

**Chronic Disease Fund, Inc.**

Provides co-payment assistance for pharmaceutical products for patients with private insurance or Medicare Part D. Currently only breast, colon, and non-small cell lung cancers and multiple myeloma are covered. Check website for more information.

1-877-968-7233 <https://pnp.mygooddays.org/>

**Heathwell Foundation**

Addresses needs of patients who cannot afford co-payments, co-insurance, and out-of-pocket medical expenses.

1-800-675-8416 [www.healthwellfoundation.org](http://www.healthwellfoundation.org)

**MedBank US**

Provides drug discount cards that allow patients with little or no prescription drug coverage to save 15%-40% on name-brand and generic prescription drugs.

912-356-2898 [www.medbank.org](http://www.medbank.org)

**National Organization for Rare Disorders (NORD)**

Helps uninsured and underinsured individuals secure life-saving or life-sustaining medications including Trisenox, Theracys, and Matulane. Covered conditions may change. Visit website for updates.

1-800-999-6673 [www.rarediseases.org](http://www.rarediseases.org)

**NeedyMeds.org**

Provides access and information on patient assistance programs for virtually all brand-name and generic medications.

[www.needymeds.org](http://www.needymeds.org) 800-503-6897

**Partnership for Prescription Assistance (PPA)**

Matches patients to programs offering free or low-cost prescription medicines.

1-888-477-2669 [www.pparx.org](http://www.pparx.org)

**Walmart \$4 List**

An extensive list of generic medications offered for only \$4 per month. <https://www.walmart.com/pharmacy/Supplies-and-Equipment/Financial-Assistance-Information>

**The Beau Beau**

“Beautiful Scarves for Beautiful Heads.” Sells fashionable scarves for women and girls with medical hair loss. 941-362-0850 [www.4women.com](http://www.4women.com)

**Breast Cancer Network of Strength**

Affiliates throughout nation provide support groups, early detection workshops, wigs and prostheses for women with limited resources. Visit website for chapter locations.

1-800-221-2141 (English); 1-800-986-9505 (Español) [www.y-me.org](http://www.y-me.org)

**The Caregivers Marketplace**

Offers cash back program for eligible products not typically covered by insurance or Medicare. Apply online for faster enrollment.

1-800-888-0889 [www.caregiver.org/caregivers-marketplace](http://www.caregiver.org/caregivers-marketplace)

**Heavenly Hats Foundation**

Provides free hats to cancer patients nationwide.

1-920-434-4151 [www.heavenlyhats.org](http://www.heavenlyhats.org)

**Where There's A Need, Inc.**

Provides hair scarves for women and children who have experienced hair loss due to chemotherapy and radiation cancer treatment or other medical conditions. Specializes in scarves for children, babies, and young adults.

718-529-3638 [www.wheretheresaneed.org](http://www.wheretheresaneed.org)











# ***Glossary & References***



# Glossary

**3-dimensional conformal radiation therapy:**

A procedure that uses a computer to create a 3-dimensional picture of the tumor. This allows doctors to give the highest possible dose of radiation to the tumor, while sparing the normal tissue as much as possible.

## A

**Abdomen:** The area of the body that contains the pancreas, stomach, intestines, liver, gallbladder, and other organs.

**Active surveillance:** Closely monitoring a patient's condition but withholding treatment until symptoms appear or change. Also called observation, watchful waiting, or expectant management.

**Adenocarcinoma:** Cancer that begins in cells that line certain internal organs and that have glandular (secretory) properties.

**Adjuvant systemic therapy:** Treatment given in addition to surgery and radiation to eliminate tumors that may have spread to other sites. There are two types, chemotherapy and hormone therapy.

**Adrenal glands:** A pair of small glands, one located on top of each kidney. They produce steroid hormones, adrenaline, and noradrenaline, which help control heart rate, blood pressure, and other important body functions.

**Agonist:** A drug that triggers an action from a cell or another drug.

**Alopecia:** Hair loss.

**Amenorrhea:** The absence or suppression of the menstrual period.

**Anastomosis:** A procedure to connect healthy sections of tubular structures in the body after the disease portion has been surgically removed.

**Androgen:** A type of hormone that promotes the development and maintenance of male sex characteristics.

**Anesthesia:** Loss of feeling or sensation. Local anesthesia may be induced into a specific region of the body, such as the breast, by injection of a

drug (a local anesthetic) into the area. General anesthesia involves the entire body and may be induced by drugs injected into a vein or inhaled.

**Angiogenesis:** Blood vessel formation, which usually accompanies the growth of malignant tissue.

**Anti-androgen:** A substance that prevents cells from making or using androgens (hormones that play a role in the formation of male sex characteristics).

**Anti-carcinogen:** Referring to an agent that counteracts carcinogens (cancer causing agents).

**Antioxidant:** Referring to an agent that counteracts oxidizing agents. Oxidizing agents are always present in the body and are beneficial. However, when large amounts of oxidants are present in cells they can cause damage, especially to DNA, which can lead to cancerous growth.

**Antiemetic:** A medicine to prevent nausea and vomiting.

**Anus:** The opening of the rectum to the outside of the body.

**Areola:** The more darkly shaded circle of skin surrounding the nipple.

**Aromatase inhibitor:** A drug used to lower the amount of estrogen in the body, so that the cancer cells cannot grow.

**Asbestos:** A natural material that is made of tiny fibers. Asbestos can cause several serious diseases, including cancer.

**Aspirate:** To remove fluid and a small number of cells.

**Atypical hyperplasia:** Overgrowth of mildly abnormal but noncancerous (benign) cells within the breast milk ducts.

**Axilla:** The underarm region.

**Axillary lymph nodes:** The lymph nodes under the arm.

**Axillary sampling (axillary dissection):** removal of some or all the lymph nodes in the armpit.

## B

**Benign:** Not cancerous. Does not invade nearby tissue or spread to other parts of the body.

**Biochemical-free survival (also known as PSA free survival or biochemical failure-free survival):** Length of time after treatment during which no detectable tumor marker (prostate-specific antigen; PSA) is found. Can be reported for an individual patient or for a study population.

**Biochemical progression (or recurrence):** The finding of an increasing amount of prostate-specific antigen, detected by comparison to its prior value, following initial treatment.

**Biological Therapy:** A therapy that targets something specific to the biology of the cancer cell, as opposed to chemotherapy, which attacks all rapidly dividing cells. Often used to describe therapies that use the immune system to fight cancer (immunotherapy). Trastuzumab (Herceptin) is an example of a biological therapy agent.

**Biomarker:** A distinctive biological or biologically derived indicator used to measure or indicate an event, effect or progress of a disease or condition. One example of a biomarker is prostate-specific antigen (PSA).

**Biopsy:** The removal of cells or tissues for examination by a pathologist. There are many different types of biopsy procedures. The most common types include: (1) incisional biopsy, in which only a sample of tissue is removed; (2) excisional biopsy, in which an entire lump or suspicious area is removed; and (3) needle biopsy, in which a sample of tissue or fluid is removed with a needle. When a wide needle is used, the procedure is called a core biopsy. When a thin needle is used, the procedure is called a fine-needle aspiration biopsy.

**Bone scan:** A test done to determine whether or not there are any signs of cancer in the bones. A small amount of radioactive material is injected into the bloodstream. It collects in the bones, especially abnormal areas, and it is detected by a scanner. Collections on bone scan may result from cancer as well as benign bone diseases like arthritis.

**Brachytherapy:** A type of radiation therapy in which radioactive material sealed in needles, seeds, wires, or catheters is placed directly into or near a tumor. Also called radiation brachytherapy, internal radiation therapy, and implant radiation therapy.

**Breast conserving surgery:** Surgery that removes only part of the breast; the part containing and closely surrounding the cancerous tumor.

## C

**Cachexia:** Loss of appetite and weight experienced by many cancer patients.

**Calcifications:** Deposits of calcium in the breast that appear on a mammogram. Microcalcifications sometime can indicate precancerous or cancerous cell growth.

**Cancer:** A term for diseases in which abnormal cells divide without control and can invade nearby tissues.

**Carcinoma In Situ:** Cancer that involves only the place in which it began and that has not spread or invaded surrounding tissues. Carcinoma in situ is an early stage tumor. In situ means “in place”.

**Catheter:** A flexible tube used to deliver fluids into or withdraw fluids from the body.

**Centigray (cGy):** One centigray describes the amount of radiation absorbed by the tissues.

**Chemoprevention:** The use of natural or synthetic substances to reduce the risk of developing disease.

**Chemoradiation:** Treatment that combines chemotherapy with radiation therapy. Also called chemoradiotherapy.

**Chemotherapy:** A drug or combination of drugs given in cycles. These drugs kill cancer cells in various ways.

**Chest wall:** The muscles, bones, and joints that make up the area of the body between the neck and the abdomen.

**Chromosome:** Part of a cell that contains genetic information. Except for sperm and eggs, all human cells contain 46 chromosomes.

**Clinical progression:** The worsening of a disease characterized by increased tissue or organ damage, biochemical markers and/or worsening of symptoms.

**Colorectal:** Having to do with the colon or rectum.

**Colostomy:** An opening into the colon from the outside of the body. A colostomy provides a new path for waste material to leave the body after part of the colon has been removed.



**Comorbidity:** The condition of having two or more diseases at the same time.

**Complimentary and Alternative Medical**

**Therapies (CAM):** Forms of treatment that are used in addition to standard treatments. These practices are not considered standard medical approaches.

**Concurrent therapy:** A treatment given at the same time as another.

**Conformal radiotherapy:** Radiation therapy shaped to increase precision of the radiation beam.

**Contralateral:** Having to do with the opposite side of the body.

**Contrast material:** A dye or other substance that helps to show abnormal areas inside the body. It is given by injection into a vein, by enema, or by mouth. Contrast material may be used with x-rays, CT scans, MRI, or other imaging tests.

**Craniotomy:** An operation in which an opening is made in the skull.

**Creatinine:** A compound that is excreted from the body in urine. Creatinine levels are measured to monitor kidney function.

**CT scan:** A series of pictures created by a computer linked to an X-ray machine. The scan provides detailed internal images of the body. Also called computerized tomography and computerized axial tomography (CAT) scan.

**Cyst:** A fluid-filled sac.

**Cytotoxic:** Toxic, or deadly, to cells (cell killing). Often used synonymously with chemotherapy.

**D**

**Diagnosis:** Identification of a disease from its signs and symptoms.

**Diagnostic Radiologist:** A physician who specializes in the study and application of imaging technology, such as ultrasound or CT, to diagnosis and treat disease.

**Dialysis:** The process of cleansing the blood when the kidneys are not able to filter the blood.

**Diaphragm:** The thin muscle below the lungs and heart that separates the chest from the abdomen.

**Digital Rectal Examination:** DRE. An examination in which a doctor inserts a lubricated, gloved finger into the rectum to feel for abnormalities.

**Distant metastasis:** The spread of cancer from the initial or primary site of disease to another part of the body.

**Dosimetrist:** A person who determines the proper radiation dose or treatment

**Duct:** A pathway in the breast through which milk passes from the lobules to the nipple.

**E**

**Erectile Dysfunction (ED):** Erections insufficient for penetration or intercourse.

**Estrogen:** A female hormone produced by the ovaries and adrenal glands. It is important to reproduction and may stimulate some cancers to grow.

**Evidence-based:** Term used to describe medical tests, procedures, and treatments that are based on sound medical scientific research studies.

**External radiation therapy:** A type of radiation therapy that uses a machine to aim high-energy rays at the cancer from outside of the body. Also called external beam radiation therapy.

**F**

**Fat necrosis:** A noncancerous tissue change in which the tissue responds to trauma with a firm, irregular mass, often years after the event. The mass is the result of fatty tissue dying, following either surgery or blunt trauma.

**Flow cytometry:** Is a technique for counting and examining microscopic particles suspended in a stream of fluid.

**Frozen section:** Process where a portion of tissue from a surgical biopsy is frozen so that a thin slice can be quickly cut and analyzed to see if it is cancerous or not. Frozen section results are only preliminary and always need to be confirmed by other methods.

**G**

**Genes:** The part of a person's cells that contains all the DNA information that determines how they grow and develop, and how their body works. The information in a person's genes is inherited from previous generations on both sides of a person's family.

**Gene mutation:** A “mistake” or “alteration” of the information contained in a gene.

**Gleason score:** A system of grading prostate cancer tissue based on how it looks under a microscope. Gleason scores range from 2 to 10 and indicate how likely it is that a tumor will spread. A low Gleason score means the cancer tissue is similar to normal prostate tissue and the tumor is less likely to spread; a high Gleason score means the cancer tissue is very different from normal and the tumor is more likely to spread.

**Grade:** The grade of a tumor depends on how abnormal the cancer cells look under a microscope and how quickly the tumor is likely to grow and spread. Grading systems are different for each type of cancer.

## H

**Hematuria:** Blood in the urine.

**HER2/neu (erbB2):** Protein that appears in high numbers on the outside of the breast cancer cells of about 20 to 25 percent of breast cancer patients. Tumors with high levels of HER2/neu are effective targets for the biological therapy drug, trastuzumab (Herceptin).

**Hormone therapy:** Treatment that adds, blocks, or removes hormones. For certain conditions (such as diabetes or menopause), hormones are given to adjust low hormone levels. To slow or stop the growth of certain cancers (such as prostate or 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. Also called hormonal therapy, hormone treatment, or endocrine therapy.

**Hormones:** Chemicals produced by various glands in the body, which produce specific effects on specific target organs and tissues.

**Hormone receptors:** A cell protein that binds a specific hormone. A high number of hormone receptors often indicate that a cancer cell needs the hormone to grow.

**Hormone receptor test:** A test used to measure the amount of certain proteins, called hormone receptors, in cancer tissue. A hormone-receptor positive cancer needs hormones to grow. A hormone-receptor negative cancer does not need hormones to grow.

**Hormone Replacement Therapy (HRT):** Postmenopausal hormones used to relieve menopausal symptoms.

## I

**Immune system:** The complex group of organs and cells that defends the body against infections and other diseases.

**Incision:** A cut made in the body to perform surgery.

**Incontinence:** Inability to control the flow of urine from the bladder (urinary incontinence) or the escape of stool from the rectum (fecal incontinence).

**Indemnity policy:** Prepayment insurance plan providing services or cash indemnities for medical care needed in times of illness or disability.

**Induction therapy (First line therapy), Primary therapy or Neoadjuvant therapy:** Initial treatment used to reduce a cancer. Induction therapy is followed by other treatments such as radiation therapy, chemotherapy, or surgery to get rid of cancer that remains.

**Inflammation:** Redness, swelling, pain, and/or a feeling of heat in an area of the body. This is a protective reaction to injury, disease, or irritation of the tissues.

**Informed consent (risks and benefits):** The process through which a patient learns about the possible benefits and side effects of a recommended treatment plan and then accepts or declines the treatment. The patient is usually asked to sign a consent document, and may decide to stop the treatment at any time and receive other available medical care.

**Intensity-Modulated Radiation Therapy (IMRT):** A type of 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.

**Intraductal:** Within the milk duct. Intraductal can describe a benign or malignant process.

**Intravenous (IV):** Being within or entering the body by way of the veins.

**Intravenous Pyelogram (IVP):** A series of x-rays of the kidneys, ureters, and bladder. The x-rays are taken after a dye is injected into a blood vessel. The dye is concentrated in the urine, which outlines the kidneys, ureters, and bladder on the x-rays.

## L

**Laparoscope:** A thin, tube-like instrument used to look at tissues and organs inside the abdomen. A laparoscope has a light and a lens for viewing and may have a tool to remove tissue.

**Laparoscopic prostatectomy:** Surgery to remove all or part of the prostate with the aid of a laparoscope. A laparoscope is a thin, tube-like instrument with a light and a lens for viewing. It may also have a tool to remove tissue.

**Lesions:** Area of abnormal tissue.

**Libido:** Sexual desire; sexual drive.

**Life expectancy:** Measure of time, usually in years or months, to define the average survival of groups of people.

**Linear accelerator:** The device used during radiation therapy to direct X-rays into the body.

**Lobectomy:** Surgery to remove a whole lobe (section) of an organ (such as brain, liver, lung, thyroid).

**Local treatment:** Treatment that focuses on getting rid of the cancer from a limited (local) area.

**Lump:** A piece or mass of indefinite size or shape.

**Lumpectomy:** See breast conserving Surgery.

**Luteinizing hormone-releasing hormone agonist:** LH-RH agonist. A drug that inhibits the secretion of sex hormones. In men, LH-RH agonist causes testosterone levels to fall. In women, LH-RH agonist causes the levels of estrogen and other sex hormones to fall.

**Lymphadenectomy:** Surgical removal of the lymph nodes that drain the organ to be removed..

**Lymphatic system:** The network of lymph nodes and vessels throughout the body.

**Lymphedema:** A condition in which extra lymph fluid builds up in tissue and causes swelling. It may occur in the arm or leg if lymph vessels are blocked, damaged, or removed during surgery.

**Lymph nodes (Lymph glands):** Small clumps of immune cells that act as filters for the lymphatic system. Clusters of lymph are found in the underarms, groin, neck, chest and abdomen.

**Lymph node status:** Indicator of whether or not cancer has spread to the lymph nodes. Lymph node-positive means that cancer has spread to the lymph nodes. Lymph node-negative means that cancer has NOT spread to the lymph nodes. See Lymph nodes.

## M

**Magnetic Resonance Imaging (MRI):** An imaging technique that uses a magnet linked to a computer to create detailed pictures of parts of the body like the liver, brain, lung, chest or any other organ suspected of having cancer.

**Malignant:** Cancerous.

**Mammogram:** An X-ray or picture of the breast either on film (standard) or stored directly onto a computer (digital).

**Margins:** The area of normal tissue surrounding the cancerous tumor after it has been removed during surgery. A margin is clear (also known as uninvolved or negative) if there is only normal tissue (and no cancer cells) at the edges of the tissues removed. Clean margins indicate that the entire tumor was removed. With involved (also known as positive) margins, normal tissue does not completely surround the tumor, and therefore the entire tumor was not removed.

**Mastectomy:** Surgical removal of the breast. The procedure depends on the patient's diagnosis. See Total Mastectomy and Modified Radical Mastectomy.

**Medical Oncologist:** A physician specializing in the treatment of cancer using chemotherapy and hormonal therapy.

**Metastasis:** Refers to cancer that has spread from the original (primary) tumor to distant organs or distant lymph nodes.

**Metastasis-free survival:** The percentage of subjects in a study who have survived without cancer spread for a defined period of time. Usually reported as time since diagnosis or treatment. Can be reported for an individual or a study population.

**Microcalcifications:** Small, clustered deposits of calcium in the breast, which may be seen on mammogram. These may or may not be associated with the breast lump. Approximately 20 to 25 percent breast cancer.

**Modified radical mastectomy:** Surgical removal of the breast, the lining of the chest muscles and some of the lymph nodes in the armpit. Used to treat early and locally advanced breast cancer.

**Monoclonal antibodies:** Immune proteins that can locate and bind to cancer cells wherever they are in the body. They can be used alone, or they can be used to deliver drugs, toxins or radioactive material directly to tumor cells.

**Multimodality therapy:** Use of two or more treatment methods (i.e., surgery, radiation therapy, chemotherapy) in combination or sequentially to achieve optimal results.

## N

**Needle localization:** Insertion of a very thin wire into an abnormal area of the breast, used to highlight the location of a nonpalpable lesion so that it can be removed during open biopsy or breast conserving surgery.

**Neoadjuvant therapy:** See Induction therapy.

**Neoplasia:** Abnormal growth.

**Neoadjuvant Hormonal Therapy (NHT):** Hormonal therapy administered prior to definitive therapy.

**Neoplasm:** Excessive number of cells in a mass that can be either benign or malignant.

**Nephrectomy:** Surgery to remove a kidney or part of a kidney. In a partial nephrectomy, part of one kidney or a tumor is removed, but not an entire kidney. In a simple nephrectomy, one kidney is removed. In a radical nephrectomy, an entire kidney, nearby adrenal gland and lymph nodes, and other surrounding tissue are removed. In a bilateral nephrectomy, both kidneys are removed.

**Nerve-sparing radical prostatectomy:** Complete removal of the prostate performed with the intent to preserve the set of nerves to the penis that affect the man's ability to have an erection and that is in close proximity to the prostate gland. Some tumors can be removed using a nerve sparing technique. Nerve-sparing surgery sometimes preserves the man's ability to have an erection after radical prostatectomy.

## O

**Oncology nurse:** A nurse who specializes in caring for people who have cancer.

**Oophorectomy:** Surgical removal of the ovaries.

**Orchiectomy:** Surgery to remove one or both testicles. Also called orchidectomy.

**Organ:** A part of the body that performs a specific function. For example, the heart is an organ.

## P

**Palliative therapy (Palliation):** A treatment given to relieve symptoms (like pain) without curing the disease.

**Partial mastectomy (Breast Conserving Therapy, Lumpectomy, Wide Excision, or Excisional Biopsy):** Surgery that removes only the part of the breast containing and closely surrounding the cancer tumor.

**Pathologist:** A doctor who identifies diseases by studying cells and tissues under a microscope.

**Pleural effusion:** An abnormal collection of fluid between the thin layers of tissue (pleura) lining the lung and the wall of the chest cavity.

**Pneumonectomy:** Surgery to remove the entire lung.

**Positive surgical margin:** The term used by the pathologist to describe the finding of cancer cells at the cut edge of the radical prostatectomy specimen. A finding of a positive surgical margin may place a patient at increased risk for cancer recurrence.

**Predictive factors:** Factors, such as hormone receptor status, which help predict the kind of treatment that will be most effective for a specific cancer case.

**Predispose:** To make more susceptible to a disease.

**Prevention:** The elimination of causes of disease from the population, so that risk of disease is either eliminated (as in the case of many infectious diseases today), or postponed until later in life (with heart disease and various cancers).

**Primary therapy:** See Induction therapy.

**Primary tumor:** The original site of the cancer.

**Prognosis:** The expected or probable outcome or course of a disease; the chance of recovery.

**Progesterone:** A hormone that helps prepare your body for conception and pregnancy and regulates the monthly menstrual cycle. Also plays a role in sexual desire.

**Progression-free survival:** The duration that a patient is alive without any objective evidence of disease progression.

**Progression (local and/or metastatic):** A change in the status indicating continuing growth or regrowth of the cancer.

**Prophylactic mastectomy:** Preventative surgery where one breast or both breasts are removed in order to keep cancer from developing. When both breasts are removed, the procedure is called bilateral prophylactic mastectomy.

**Prostate-Specific Antigen (PSA):** A substance produced by the prostate that may be found in an increased amount in the blood of men who have prostate cancer, benign prostatic hyperplasia, or infection or inflammation of the prostate.

**Prostate-Specific Antigen (PSA) failure:** The state in which the serum level of PSA does not respond appropriately to therapy; this could be failure to drop or to stabilize or could be a continuous rising level.

**Prosthetic, breast:** An artificial breast form that can be worn under clothing after a mastectomy.

**Protocol:** An outline or plan for use of an experimental drug, treatment or procedure in cancer therapy or diagnosis.

## Q

**Quadrantectomy:** Surgery where one quadrant or 25% of the breast is removed. See Breast conserving therapy.

## R

**Radiation Oncologist:** A physician specializing in the treatment of cancer using high energy X-rays.

**Radiation Therapy (Radiotherapy):** Treatment given by a radiation oncologist using radiation to kill or damage cancer cells in the area exposed. Radiation may come from a machine outside the body (external beam radiation therapy), or it may come from radioactive material placed in the body near cancer cells (internal radiation therapy). Systemic radiation therapy uses a radioactive substance, such as a radiolabeled monoclonal antibody, that travels in the blood to tissues throughout the body. Also called radiotherapy and irradiation.

**Radical nephrectomy:** Surgery to remove the entire kidney, the adrenal gland, and other surrounding tissue. Sometimes nearby lymph nodes are also removed.

**Radical prostatectomy:** Radical prostatectomy is the complete surgical removal of the entire prostate gland that may be performed through an open incision or through a laparoscopic approach.

**Radiotherapy:** See Radiation Therapy.

**Reconstruction:** A way to recreate the breast's shape after a natural breast has been removed. Various procedures are available, some of which involve the use of implants. May also be referred to as reconstruction mammoplasty.

**Rectum:** The last several inches of the large intestine. The rectum ends at the anus.

**Recurrence:** Return of cancer. Local recurrence is the return of cancer to the same breast or chest wall. Distant recurrence is the return of cancer to another location such as the lungs or liver. See Metastasis.

**Registered Dietitian:** A health professional with special training in the use of diet and nutrition to keep the body healthy. A registered dietitian may help the medical team improve the nutritional health of a patient.

**Regression:** The shrinking of a tumor.

**Remission:** A temporary or permanent disappearance of the signs and symptoms of cancer.

**Risk (of disease):** Probability of disease developing in an individual during a specific time period.

**Risk-benefit ratio:** The relationship between the possible (or expected) side effects and benefits of a recommended treatment or procedure.

**Risk factor:** Any factor—from a lifestyle choice (such as diet) to genetic make-up to an environmental exposure (such as radiation)—that increases a person's risk of developing a certain disease.

## S

**Screening:** A test or procedure used to detect cancer or a precancerous condition in an apparently healthy person without symptoms. The goal of screening is to identify a disease in its early stages to improve the likelihood of cure and/or prevention of complications from the disease.

**Secondary primary tumor:** A second cancer that arises in a different location from the first. Different from a local recurrence, which is the return of the first cancer.

**Second-line therapy:** Can include definitive and palliative treatments. Includes any treatment that is offered following evidence of disease recurrence or progression after initial treatment.

**Side effect:** A problem that occurs when treatment affects healthy tissues or organs. Some common side effects of cancer treatment are fatigue, pain, nausea, vomiting, decreased blood cell counts, hair loss, and mouth sores.

**Simulator (for Radiation Therapy):** A clinical X-ray unit used to define the exact treatment area for radiation therapy.

**Sonogram:** A computer picture of areas inside the body created by bouncing high-energy sound waves (ultrasound) off internal tissues or organs. Also called an ultrasound.

**Staging:** Performing exams and tests to learn the extent of the cancer within the body-its stage. Knowing a cancer's stage helps to determine what treatment may be necessary and how effective this treatment may be in getting rid of the disease and prolonging life.

**Standard treatment:** the usual treatment currently in widespread use and considered to be of proven effectiveness on the basis of previous experience.

**Stem cell transplantation:** A method of replacing immature blood-forming cells that were destroyed by cancer treatment. The stem cells are given to the person after treatment to help the bone marrow recover and continue producing healthy blood cells.

**Stem cells:** Cells from which other types of cells can develop.

**Supportive care:** Care given to improve the quality of life of patients who have a serious or life-threatening disease. The goal of supportive care is to prevent or treat as early as possible the symptoms of the disease, side effects caused by treatment of the disease, and psychological, social, and spiritual problems related to the disease or its treatment. Also called palliative care, comfort care, and symptom management.

**Surgeon:** A doctor specially trained to remove or repair a part of the body by operating on the patient.

**Surgery:** A procedure to remove or repair a part of the body or to find out whether disease is present. An operation.

**Symptom management:** Care that prevents or relieves the symptoms of disease or the side effects of treatment. Symptom management does not attempt to cure a disease but can improve a patient's quality of life. It attempts to meet the physical, emotional, spiritual, and practical needs of patients by helping to relieve pain, depression, or other problems. Also known as palliative care, comfort care, and supportive care.

**Systemic treatment:** Treatment of the whole body with substances that travel through the bloodstream and affect cancer cells all over the body.

## T

**Targeted therapy:** Treatment that works by going to the genes and proteins in cancer cells to stop their growth and spread.

**Testosterone:** A hormone that promotes the development and maintenance of male sex characteristics.

**Thoracoscope:** A thin tube-like instrument used to examine the inside of the chest. A thoracoscope has a light and a lens for viewing and may have tool to remove tissue.

**Thoracotomy:** A surgical procedure used to open the chest.

**Total androgen blockade:** Therapy used to eliminate male sex hormones (androgens) in the body. This may be done with surgery, hormonal therapy, or a combination.

**Total mastectomy (Simple mastectomy):** Surgical removal of the breast but no other tissue or nodes. Used for the treatment of ductal carcinoma in situ and, in some instances, recurrent breast cancer. Also the procedure used in prophylactic mastectomy.

**Transfusion:** The infusion of components of blood or whole blood into the bloodstream. The blood may be donated from another person, or it may have been taken from the person earlier and stored until needed.

**Transplantation:** The replacement of tissue with tissue from the person's own body or from another person.

**Transrectal ultrasound (TRUS):** TRUS. A procedure in which a probe that sends out high-energy sound waves is inserted into the rectum. The sound waves are bounced off internal tissues or organs and make echoes. The echoes form a picture of body tissue called a sonogram. TRUS is used to look for abnormalities in the rectum and nearby structures, including the prostate. Also called endorectal ultrasound and ERUS.

**Tumor:** An abnormal growth or mass of tissue that may be benign (noncancerous) or malignant (cancerous).

**Tumor grade:** Describes how closely a cancer resembles normal tissue. The higher the grade, the less it resembles normal tissue, and the faster the cancer's rate of growth is likely to be.

## U

**Urologist:** A doctor who specializes in diseases of the urinary organs in females and the urinary and sex organs in males.

## V

**Vaccine:** A substance or group of substances meant to cause the immune system to respond to a tumor or to microorganisms, such as bacteria or viruses. A vaccine can help the body recognize and destroy cancer cells or microorganisms.

## W

**Watchful waiting:** Closely monitoring a patient's condition but withholding treatment until symptoms appear or change. Also called observation.

**Wedge resection:** A surgical procedure to remove a triangle-shaped slice of tissue. It may be used to remove a tumor and a small amount of normal tissue around it.

## X

**X-ray:** Radiation that can be useful, at low levels, in the diagnosis of cancer and, at high levels, in its treatment.









