

# LIVING WITH CANCER

GUIDEBOOK



Phelps Health  
DELBERT DAY CANCER INSTITUTE

This cancer patient guidebook is provided courtesy of the Phelps Health Delbert Day Cancer Institute, your physician(s) and care team.

Please bring this book with you to:

- Your visits to Phelps Health for a new procedure or treatment
- Your visits to a physician you are seeing related to cancer treatment

# Greetings!

This guidebook was written to help you understand your diagnosis of cancer. We also hope it will help you prepare and recover from the treatments you may have ahead of you. There is detailed information on chemotherapy, radiation therapy, surgery and other treatments related to cancer. We'll also tell you about the different roles of the people on your healthcare team and give you references for additional support on your journey through treatment. We hope this guidebook will help you feel more comfortable, physically and emotionally, in this journey with us.

While the physicians and staff at the Phelps Health Delbert Day Cancer Institute (DDCI) offer comprehensive cancer care, we believe you play a key role in having successful treatment. By educating and involving yourself in each step of the process, you will be better prepared to work with your healthcare team more effectively and will feel more secure that you are on the appropriate path through treatment.

We have an excellent staff ready to help you in your fight with cancer. This team includes surgeons, radiation oncologists, medical oncologists, oncology nurses, radiation therapists, pharmacists, nutritionists, diagnostic radiologists, social workers, cancer educators, chaplains and rehabilitation staff. These people know a lot about the challenges and stresses you may face and are eager to answer your questions and help you in any way they can. Don't be embarrassed to ask questions. Your experience will go more smoothly if you know what to expect. Your feedback also will help us know if this guidebook addresses your concerns.

Please share this guidebook with your loved ones. It will answer many of their questions and will help them assist you on the path through treatment and recovery. They may even prompt you to think of more questions to ask your healthcare team. This book also is available online at [phelpshealth.org](http://phelpshealth.org).

-Jeremy Stinson, Director of the DDCI

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**IMPORTANT:** The materials in this book have been reviewed by specialists in oncology care, including board-certified oncologists and nurse educators certified by the Oncology Nursing Society. This guidebook is not intended as a substitute for care but rather should be seen as a reference to be used along with treatment prescribed by your physicians. Please review this guidebook's contents with your physicians and other members of your healthcare team so that you understand how it relates you and your good health.



Each section is color-coded to aid in navigation

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# PHELPS HEALTH/ DDCI INFORMATION

Phelps Health employs a staff of over 1,800 and is licensed for 242 patient beds. Phelps Health is staffed 24 hours a day, seven days a week, providing exceptional healthcare services to the community. With modern diagnostic and treatment techniques, the Phelps Health Delbert Day Cancer Institute (DDCI) offers a comprehensive set of services for cancer patients and their families.

## About Phelps Health

Phelps Health, located in Rolla, is one of Missouri's leading regional referral centers, serving over 200,000 residents in south-central Missouri. Phelps Health is a non-tax supported, county-owned hospital with a five-member elected board of trustees. Phelps Health has clinics in Rolla, Salem, St. James, Vienna and Waynesville.

The Phelps Health Medical Group, comprised of more than 100 providers and 25 specialties, is equipped to deal with complex medical ailments. The exceptional providers are focused on ensuring wellness, from prevention through diagnosis, and into recovery. The Phelps Health Medical Group is dedicated to providing patients with a lifetime of care, close to home.

## About the Delbert Day Cancer Institute

The Delbert Day Cancer Institute (DDCI) opened in January 2017 on the Phelps Health campus in Rolla. The facility is located just north of the Medical Office Building and faces Interstate 44. The four-story, 100,000-square-foot building houses all of Phelps Health's cancer care services and cutting-edge technology under one roof. This allows for convenience and continuity of care for patients and their families.

The DDCI is named after Dr. Delbert Day, curators' professor emeritus of ceramic engineering at Missouri University of Science and Technology. The DDCI has earned national accreditation from the Commission on Cancer of the American College of Surgeons.

Services and amenities at the DDCI include radiation oncology, medical oncology and hematology, chemotherapy, radiation therapy, laboratory and diagnostic imaging services, infusion center, pharmacy, physician offices and areas for a community conference center, cancer rehabilitation, genetic counseling, nurse navigation, social workers, cancer resource center, dietary support, spiritual support, wig and bra fitting boutique, A New Day Café and more.



### Phelps Health Delbert Day Cancer Institute

1060 West 10th Street

Rolla, Missouri 65401

Phone: (573) 458-3324 (DDCI)

Toll-Free: (855) 406-3324 (DDCI)

[phelpshealth.org](http://phelpshealth.org)



## Siteman Cancer Center

4921 Parkview Place  
St. Louis, MO 63110  
Phone: (800) 600-3606  
[siteman.wustl.edu](http://siteman.wustl.edu)



*Access to clinical trials at Siteman Cancer Center will help patients living in south-central Missouri.*

## SITEMAN CANCER NETWORK

The Phelps Health Delbert Day Cancer Institute (DDCI) is part of the Siteman Cancer Network, an affiliation led by Siteman Cancer Center at Barnes-Jewish Hospital and Washington University School of Medicine in St. Louis.

The Siteman Cancer Network is committed to improving the health and well-being of people and communities by expanding access to cancer research, treatment and prevention initiatives.

Through this partnership, patients in south-central Missouri with complex cases or rare types of cancer will have greater access to highly specialized care and treatments offered at Siteman Cancer Center.

### Key Components of the Network Affiliation Include:

- Navigators to help patients coordinate access to highly specialized care for complex cases, including access to clinical trials, at Siteman Cancer Center.
- Use of genomic and genetic testing to help identify personalized treatments based on the characteristics of a patient's disease.
- Development of a database that incorporates such information (with patients' permission) to improve clinical care and patient outcomes.
- Sharing of best practices to improve patient care. Examples include sharing details regarding how nurses and radiation therapists are trained to care for oncology patients, and implementing industry-approved guidelines for screenings, genetic counseling programs and post-treatment care.
- Implementation of cancer prevention strategies, such as the use of interactive risk-assessment tools, e-books, videos and individual coaching.
- Development of targeted interventions to reduce cancer risk and of evaluation tools to measure success.

As partners in this network, Siteman and Phelps Health are working together on strategies to better control the spread of cancer, reduce the burdens of cancer on patients and their loved ones and increase the number of patients screened for cancer, all of which will help lead to earlier detection and healthier outcomes in the community.



To learn more about the Siteman Cancer Network, please visit [siteman.wustl.edu/visiting/network](http://siteman.wustl.edu/visiting/network)

## CANCER PROGRAM OVERVIEW

The Phelps Health Delbert Day Cancer Institute (DDCI) offers a comprehensive cancer program that includes the following services:

- Diagnostic radiology, including Magnetic Resonance Imaging (MRI) and Computed Tomography (CT or CAT) scanners
- Nuclear imaging, including Positron Emission Tomography (PET) scanner
- Pathology (tumor analysis) and other laboratory services
- Surgical services
- Outpatient radiation therapy, including brachytherapy radiation therapy
- Outpatient chemotherapy
- Dedicated inpatient cancer care nursing unit

Some special elements of the cancer program include:

- Nurses and therapists who specialize in the care of cancer patients' unique needs
- A comprehensive cancer patient guidebook for use at Phelps Health and home
- A patient journal to help you track your progress through treatment and recovery
- Clear and concise educational brochures and videos
- Nurse navigator, social worker, nutritionist and chaplain services
- American Cancer Society programs like "Look Good Feel Better" held on site (ask about the latest schedule)
- Support group meetings held on site (see listing in the back of this guidebook in the Support Services section)

## ABOUT THE DDCI INFUSION CENTER AND RADIATION ONCOLOGY DEPARTMENTS

**Hours:**

Medical Oncology: Monday-Friday 8:00 AM - 4:30 PM

Radiation Oncology: Monday-Friday 7:30 AM - 4:00 PM

DDCI Infusion Center - Monday-Friday 8:00 AM - 4:30 PM

**The Phelps Health DDCI is closed on weekends and evenings and follows an adjusted holiday schedule.**

**Phone/Fax Numbers:**

Radiation Oncology: (573) 458-7500

Toll-free: (888) 839-8090

Fax: (573) 458-8363

Medical Oncology/Hematology: (573) 458-3324

Toll-free: 1 (855) 406-3324

Fax: (573) 458-8445

The DDCI phones have a voice message system after hours and on weekends for non-emergent messages. **For an emergency, call 911.** Please do not hesitate to call if you think you may have a medical problem that should not wait until regular office hours.

**Address:**

Phelps Health  
Delbert Day Cancer Institute  
1060 West 10th Street  
Rolla, MO 65401

**Parking:**

There are patient parking spaces in front of the DDCI. Patients may be dropped off under the covered circle drive. Patients and visitors can park in front of the facility in the Purple Lot.

Wheelchairs are available for your use in the lobby. Your nurse will provide you with scheduled times for your appointments. Your time for your radiation treatment will generally be the same every day. If you need to change your appointment for any reason, please let us know.

If you come in for treatment or a check-up and feel you have waited too long, please ask the receptionist to see what the delay might be. There is a television and telephone in the waiting area. A New Day Café on the ground floor of the DDCI offers selected Starbucks coffee, other refreshments as well as light meals and snacks.

If you have questions, suggestions or comments that may make your time with us easier, please mention this to your radiation therapists, nurses or the receptionist. We are eager to help in any way we can.





## AT PHELPS HEALTH AND THE DDCI

### What You Should Bring:

**Chemotherapy Outpatients:** Unless told otherwise, your chemotherapy will be delivered at the Phelps Health Infusion Center on the first floor of the DDCI. You will normally be seated in a reclining chair for your chemotherapy. Wear comfortable, non-binding clothing. Ask your nurse about the best clothes to wear for the treatments. You may bring in your own books, magazines or computer and earphones to entertain yourself. Wi-Fi is available for your convenience. You may invite an adult loved one to stay with you and talk quietly during your treatment.

**Radiation Therapy Outpatients:** The clothing you should wear will depend on the area to be treated. Some patients will be required to change into a gown; others will be able to wear normal street clothing (skirt and blouse or pants and shirt) and be asked to move the clothing aside to make your treatment planning marks visible. Ask your radiation therapist about the best clothes to wear for treatments.

**Inpatients:** We suggest you bring comfortable bedclothes, including a robe, pajamas or nightgown, and slippers. We supply toiletries, but you may bring your own to use. You might wish to bring in your own books or magazines for entertainment. **The most important item to bring is a list of your medications and nutritional supplements.** Be sure to include the correct name, dosage and frequency. Please

include any over-the-counter medications and herbs you take as well. A sample medication list is available in the back of this guidebook.

### Visiting Hours:

We encourage patients to be visited by friends and family. Please try to observe our visiting hours. If you require an exception, please speak to the nurse on duty. Please have no more than two visitors at a time with a patient. An adult must accompany children in lobby areas. No smoking is allowed on all Phelps Health property. Please speak in quiet tones and be considerate of other patients.

At the DDCI Infusion Center, visitors must be age 16 or older. Visitors must be free of infections or communicable diseases and follow the directions of staff and physicians. Visitors also should be mindful of maintaining a calm environment.

**Phelps Health General Visiting Hours:** 9:00 AM to 9:00 PM  
**Intensive Care Unit (ICU) Visiting Hours:** 10:00 AM to 9:00 PM

Phelps Health General Operator Phone (for connection to patient rooms): (573) 458-8899

## INSURANCE/ACCOUNT BILLING

### Please Be Advised

Many insurance companies require the patients they cover to have an approved referral form before seeing a specialist (like a radiation or medical oncologist). They also sometimes require pre-authorization before diagnostic testing can be performed. Diagnostic testing can include CT scans, bone scans or MRI scans.

It is your responsibility to make sure any necessary referrals or pre-authorizations are obtained before the services are provided so as to meet the requirements of your insurance company.

### **Policy for Account Billing and Insurance Filing**

You will be charged by two separate billing offices for your radiation therapy. Since the Radiation Oncology Department is a part of Phelps Health, you will be billed by Phelps Health for the hospital's portion of each charge. These are technical charges for treatments, devices used, treatment planning, etc. You also will receive a bill from the Phelps Health Medical Group for the doctor's professional fees for services performed.

You must sign an authorization form for both the hospital and doctor to file your primary and secondary insurance for you. This will generally be done when you check in for your first visit to the Radiation Oncology Department.

For questions regarding Phelps Health billing, please call (573) 458-8899, extension 5300. There are billing specialists who are available to assist with insurance questions and to work out payment plans, if needed.

## **YOUR RIGHTS AS A PATIENT**

### **Patients' Bill of Rights**

The law requires every healthcare provider or facility to provide you with a copy of the "Patients' Bill of Rights and Responsibilities." These rights and responsibilities are reviewed with you at the time of admission to the hospital and signed by you and the admitting personnel. The document you sign will list your rights while you are a patient in the hospital as well as your responsibilities. You may request a copy of these rights and responsibilities be sent to you in advance of your admission to give you time to review and understand them at your leisure. If at any time you feel the hospital or a healthcare provider that treats you there has violated your rights, you may contact your state's Consumer Assistance Unit to report any problems.

### **Informed Consent**

As a patient, you have the right and responsibility of informed participation in decisions involving your healthcare. This participation should be based on a clear, concise explanation of your condition. The

healthcare provider should explain all of the proposed procedures and medications to be used for treatment. This explanation should include any risks, side effects and problems related to recuperation and the probability of success or failure with the treatment. You should not undergo any treatment without you or your legal representative's voluntary and complete understanding of the consent process and treatments being proposed.

## **ADVANCE DIRECTIVES**

At the time of admission, you will be asked if you have any "advance directives" in place. These are legal documents that tell your doctor your wishes about medical treatment when you are unable to communicate these decisions or choices yourself. Generally, these documents are signed in advance of treatment to let your doctors and healthcare team know your wishes. For example, if you fell into a coma, they would let the doctor know your wishes for care or say who you would wish to make the decisions for your care.

Advance directives are not required for admission to the hospital, but we strongly recommend that you have these documents in place. Admissions personnel can provide you the forms for this state and instructions for having them completed so they are legally binding.

It is important that you discuss your wishes with your loved ones so they will respect these documents if they are called into use, especially if you are naming someone to act on your behalf. Make sure you give copies of these directives to your family, doctors and any healthcare facilities where you receive treatment. You can change your mind any time after creating these directives. Simply destroy the original and let your family, doctor and anyone else with copies know of your change of mind.

These directives only go into effect when you are no longer able to make your own healthcare decisions (or no longer able to provide informed consent). These advance directives will be placed in your patient chart, but it is important that you make your healthcare providers aware that you have made advance directives.

Missouri law recognizes two types of advance directives: a Living Will Declaration and a Durable Power of Attorney.

If you do not make any advance directives, there is a chance you may receive life-prolonging procedures that you might not wish to have.

**If you have no advance directives, your healthcare providers will look to others to make life-prolonging care decisions in the following order:**

- Your guardian, if the court has appointed one, or a healthcare surrogate you have appointed
- Your spouse
- An adult child (or if you have more than one, the doctor will seek opinions from all who are reasonably available to consult)
- Either of your parents
- An adult sibling (or if you have more than one, the doctor will seek opinions from all who are reasonably available to consult)
- Any other of your adult relatives who have shown special care or concern for you and who are familiar with your activities, health, religious or moral beliefs
- A close friend who has shown special care or concern for you and who is familiar with your activities, health, religious or moral beliefs

**The following are descriptions of these advance directives:**

**Durable Power of Attorney:** If you have a durable power of attorney which appoints someone to make healthcare decisions for you, do you still need a living will or other advance directives? The answer is yes. Whether or not you have a power of attorney does not affect the need or desire for a living will or other advance directives. If you do not have a power of attorney, your advance directives will be very helpful to instruct your physician and the hospital as to the care you desire. If you do have a power of attorney, your advance directives will give very important guidance to your attorney-in-fact as to how he or she should act. In fact, you may want to combine your power of attorney, your living will and your other advance directives into one document.

**Living Will Declaration:** A living will expresses your desire to not have your dying be artificially prolonged under specific sets of circumstances, such as when two or more doctors agree that there is no medical probability of your recovering from a terminal (life-ending) medical condition. A living will generally requests that only comfort or pain relief measures be given in such a circumstance, and that your dying be allowed to occur naturally. You may provide additional instructions in such a living will, such as a certain time period to allow particular rescue measures to be used before stopping their use.



# AFTER DIAGNOSIS

Now that you have been given a diagnosis of cancer, the question of how to treat your cancer lies in the hands of both you and your healthcare team. For many types of cancer, there is no one “right” treatment. You may have several options, each with benefits and risks attached.

You want to make sure your healthcare team uses the appropriate treatment(s) for you. Finding out about your particular type of cancer is a great way to participate knowledgeably in discussions about treatment. Your doctors, nurses and social workers are excellent sources of information. In addition, this guidebook provides extensive information about the many treatments for cancer and dealing with their side effects. The Support Services section of this guidebook lists many local and national organizations dedicated to helping patients and their families cope with diagnosis, treatment and survivorship. Your local library also may be a good source for information.

## WHAT IS CANCER?

Cancer is a disease that occurs when the cells of the body begin to divide and multiply in an uncontrolled way. Normally, cells have a defined life cycle. At the end of that cycle, they naturally pass away. This planned cell death is called apoptosis. In cancer, this death is delayed or does not happen for some cells. Without the “off switch,” these cancerous cells continue to divide and multiply, which may cause tumors. Given time, cancerous cells often develop the ability to distribute themselves to other parts of the body. We call this spread of cells from the original cancer site metastasis.

**Cancer can metastasize in three ways:** through the lymphatic system, through your blood vessels (the venous system) and by directly passing from one organ to another.

When cancer spreads through the lymphatic system, it is carried by lymph fluid that flows through lymph vessels to most parts of your body. The role of the lymphatic system is to help fight impurities and infections. The lymph vessels pass through lymph nodes, which work like filters in the system. Cancer cells may be caught, stay and grow in these nodes, or sometimes they will spread, or metastasize, to other parts of your body. For example, breast cancer may spread via the lymphatic system to the lymph nodes in the axilla (armpit). If the cancer is not treated, it may spread onward to lymph nodes in other parts of the body.

The second way cancer may spread is through the venous system. For example, if left untreated, a cancerous tumor in the breast may shed cancerous cells into the veins of

the breast. The cells then may be carried by the blood vessels through the heart and then lodge in the left lung, causing a secondary cancer to grow there.

Cancer also may spread by direct extension from one organ to another. In this breast cancer example, a primary cancer of the breast may spread directly to the chest wall behind it.

### Why Does Cancer Make People Sick?

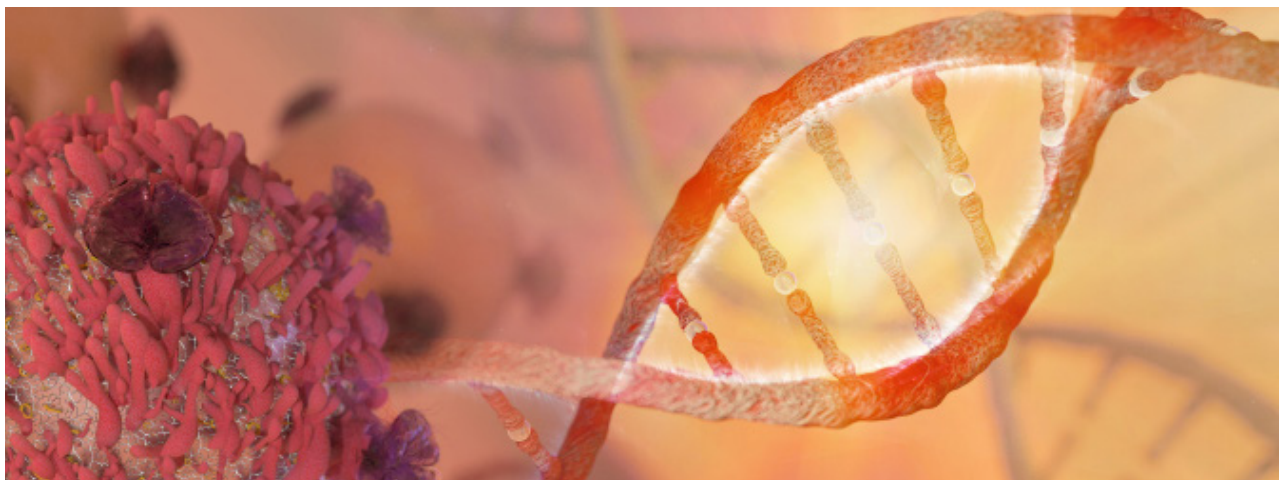
Cancer makes people sick because the cancerous cells take the place of healthy cells. Cancerous cells use up the energy and oxygen your normal cells need to keep going. This stealing process is one reason people with cancer may be very tired or fatigued and lose weight. If a tumor becomes large enough, it may press on important nerves, causing pain. A tumor may take over the cells of a healthy organ, slowing or preventing the organ’s normal function. This is why someone with lung cancer may find it hard to breathe.

### What Causes Cancer to Happen?

Cells stop their normal life cycle process because of changes in their genetic makeup. Sometimes we inherit genes from our parents that are not perfect and make us more likely to get cancer. Environmental factors can damage cells; for example, getting too many sunburns and suntans may damage skin cells. Not everyone with inherited flaws or exposure to damaging environments gets cancer. It requires a sequence of changes in multiple genes to start a cancer. This is why we see some heavy smokers live until they are very old and never get cancer, and others develop lung cancer very young.

Genes that cause cancer when they have changed or





mutated are called oncogenes. Another way cancer develops is when tumor suppressor genes, the natural “brakes” we have to prevent cancer, develop mutations. Every type of cancer has a unique set of genetic mutations associated with it, but some changes are seen in a number of cancers, such as the p53 gene mutation. No one mutation has yet been identified that is associated with every cancer.

## WORKING WITH YOUR DOCTOR

To go successfully through diagnosis, treatment and recovery, you need to develop trust and confidence in your doctor(s). The best way to do this is communicate. Your doctor will be your best source for education about your cancer and its treatment, so you need to have confidence that your doctor welcomes your questions. Your concerns are important to you and your doctor.

### Medical and Personal History

You should be very open and honest in discussing your medical history with your healthcare team. Detailed information about illnesses in your blood relatives, your own past illnesses, and your eating, drinking and smoking habits will be very helpful to the doctor. Be sure to mention any medications and nutritional supplements you are taking. You may even bring the containers in so the doctor can clearly understand what you are taking. It also is important to share what your home and work life is like and the stresses you live under each day. This will let your healthcare team help you plan for support during and after treatment. If you are concerned about having

children or being able to perform particular activities in the future, be sure to let your doctor know.

### Symptom Discussion

The more clearly you can describe your symptoms to your doctor, the more easily the doctor will be able to determine the correct diagnostic tests to use to evaluate your health. Many patients find a journal to be a good place to note their symptoms to then inform their doctors. When describing your symptoms, be sure to mention the following:

- Precise symptom location
- Frequency of the symptom
- Associations (“It hurts when I cough,” etc.)
- Characteristics (sharp, dull, tingly, burning, warm, numb, etc.)
- Triggering events (“Right after I take my medicine” or “When I wake up”)
- What makes the symptom seem to go away (“The medicine stops the pain quickly”)

### Bring In Questions and Take Notes

Your time is valuable and so is your doctor’s, so it is helpful to be organized when you go in for an exam. In the days before your exam, make a note of any questions you have about your treatment, about symptoms you are having or about your medications. Bring your list of questions to the appointment. In the back of this guidebook, there is space to write down your questions. If making a list is difficult, talk about your concerns with a family member or friend and invite them to come

along to help you present your questions. Take notes, or have a friend/family member take notes about the doctor's comments and instructions. You may wish to ask your doctor if you may bring in a small tape recorder to record the doctor's comments for review after your appointment. Remember, do not be embarrassed to ask any questions about what is going on with your body or your treatment.

**Here are some questions you may wish to ask your doctor. We have tried to answer many of these questions here in the guidebook, but your doctor will need to answer some of them directly.**

### Diagnosis

- What type of cancer do I have, and what is its medical name?
- What is the stage of my cancer? How far developed is it? How was the stage determined?
- Has the cancer spread beyond its original site? If so, how do we know where it has gone?
- Do I need additional tests to check if the cancer has spread beyond its original site?

### Tests

- What tests or examinations have demonstrated I have cancer?
- What are the risks for the tests you recommend? What complications should I watch for during or after the test?
- Will these tests leave a scar? If so, where will the scar be and what will it look like?

### Treatment

- What are my treatment options? What are their short- and long-term risks?
- What are the treatment's short- and long-term physical side effects? How will they be managed? Which side effects should I report immediately?
- What are the treatment's emotional side effects? How will they be managed?
- How much time can I take to decide between options without jeopardizing my health?
- How long will treatment take? Will I be able to work during treatment?

- If a biopsy is positive, will you want to remove the rest of the cancer right away?
- What are the treatment goals?
- What types of doctors will be involved in treating me?
- How will we know if the treatment is successful?

### Evaluation

- Assuming we are successful in treating the cancer, how will I be monitored for recurrence?
- What symptoms should I look for as signs of recurrence?

For additional suggestions about working well with your healthcare team, please refer to the following resource by the National Coalition for Cancer Survivorship (NCCS) titled "Teamwork: The Cancer Patient's Guide to Talking with Your Doctor" (©2011). A PDF version of this resource is available at this website:  
<http://www.canceradvocacy.org/wp-content/uploads/2013/01/Teamwork.pdf>

Contact information for NCCS is in the Support Services section of this guidebook.

## EMOTIONS AND CANCER

The emotional side of fighting cancer is in many ways as challenging as the physical side. Your doctor is there to support you, as are social workers, oncology nurses and other people on your healthcare team.

People close to you are likely to be your strongest sources of emotional support—family members, friends, neighbors and church members. There are numerous local and national organizations that can put you in touch with others who are cancer survivors or who also have just been diagnosed with cancer (see the listing in the back of this guidebook).

Support may be by phone or in person, or in a support group. If you have access to a personal computer, there are Internet-based cancer support groups, some general and some for particular cancers and side effects. Please be aware that these "online" support groups will sometimes discuss treatments that are not scientifically

proven to be safe and effective, so if you hear something interesting, be sure to discuss it with your healthcare provider.

Sometimes people have trouble asking for help. If this is an issue for you, think about specific things people can do for you. Make a list of the things you could use help with and then start asking those closest to you to help, starting with the easiest thing on the list. You may be surprised how willing people are to help.

Sometimes talking with an oncology social worker or a psychologist also can provide emotional support. A social worker may help you deal with sadness, depression and feelings of being overwhelmed. Social workers can offer talk therapy, make suggestions for behavior modification that can help you feel better or may work with your doctors to obtain medications that may positively influence your mood. Medications that target anxiety and depression can be considered by discussing your emotional distress with a doctor.

### When Coping Is Difficult

Some emotional illnesses can emerge out of the stress of having cancer. **These illnesses are often treatable, so be sure to speak to your doctor if you or someone you care for appears to be suffering from these problems:**

- **Anxiety disorder:** Too much worrying can stop patients from enjoying their lives. It may even interfere with seeking the treatment they need.
- **Panic attacks:** An individual who experiences panic attacks may have a sudden overpowering feeling of fear or anxiety that prevents him or her from functioning.
- **Post-traumatic stress disorder:** After a very stressful event, such as having cancer and being treated for it, a person can have a strong negative reaction. This reaction might include persistent nightmares or unpleasant memories. Someone with this disorder may avoid any reminder of cancer and may withdraw from loved ones or follow-up care.
- **Depression:** Major depression, in which people feel

so hopeless that they cannot function normally, may be a problem for cancer patients. If you have strong feelings of guilt, worthlessness or hopelessness; feel suicidal; or cannot feel pleasure for two weeks or more, you may have depression and should talk to your doctor. Other symptoms of depression can include: feeling low on energy, sleeping too much or too little, worrying all of the time, crying frequently and rapidly gaining or losing weight. Depression may be treated with medicine and non-medicine therapies, so tell your doctor if you think you are severely depressed.

- **Situational depression:** Our lives are full of risky events and situations that cause stress. A change in your health can cause stress and depression.

## TALKING TO FAMILY AND FRIENDS

Your family and friends will usually be your strongest sources of support as you go through diagnosis and treatment. Their support can range from helping around the house and going to exams with you to simply listening to how you feel. As you share the news of your cancer with your family and friends, be aware that they have different ways of coping with difficult news and the challenge that cancer represents. Some friends may be scared by your cancer and pull away as you go through treatment, while others will become better friends to you as they respond to your need for support.

Maintain honest two-way communication with your loved ones. If you and others express your emotions honestly, you can all gain strength from each other. Normal schedules and family roles may be changed as treatment and its side effects occur. It is helpful to talk to each person in the family about the changes ahead as you begin your journey into cancer treatment.

If you share that a treatment may cause a change in mood, for instance, this will help everyone maintain a smoother relationship with you. They may be able to better understand where an unexpected mood is coming from. The challenge of cancer may actually become an opportunity for you and your family to become closer

as you express your care and love for each other in new ways.

Learn to accept your family and friends' help. Accepting help from others to run errands, prepare meals, or help with household chores gives others a sense of making a contribution at a difficult time.

### **Talking to Children about Cancer**

Certainly one of the most difficult things to do is to tell a child that a family member has cancer. Children need to hear different amounts of information, depending on their maturity and ability to understand. They will notice if a loved one has less time for them, is unhappy or moody, or looks or acts sick.

Having a conversation before the child finds reason to question a parent being ill is the best thing. If you do not tell the child anything, he or she may question whether the change in the loved one is somehow his or her fault. Younger children are especially susceptible to thinking that something they have thought or done may have caused a problem. Older children often want to be included when major events happen to the family and welcome the opportunity to be of help.

When speaking to children, use simple, age-appropriate language. Try to stick close to the truth, especially regarding how serious the situation may be. You may have to repeat this information a few times for it to sink in, particularly if it is not happy news. It is good to repeat that it is "no one's fault" that the loved one is sick.

## **TALKING TO YOUR EMPLOYER**

If you are in the workplace, you will need to make a decision about what to tell your employer about your cancer diagnosis. Some patients choose to be very open and let all of their co-workers know, while others choose only to provide the amount of information needed to their direct supervisor or human resources department to allow going to treatment.



### Taking Time off from Work

The 1993 Family and Medical Leave Act allows employees with serious medical conditions to take a total of 12 weeks of unpaid leave per year without risking their positions. This law applies only to workplaces of 50 or more employees, and companies may exempt (not include) their highest paid employees. You must have worked at least 25 hours per week for one year to qualify for this leave. If you have questions about this law, please contact the local U.S. Department of Labor, Employment Standards Administration, Wage and Hour Division. You also may find more information online at [http://www.dol.gov/esa/public/whd\\_org.htm](http://www.dol.gov/esa/public/whd_org.htm).

### Job Discrimination

The United States passed the Americans with Disabilities Act (ADA) in 1992 to ensure that employees who have a disability because of illnesses are not unfairly discriminated against. Employers with 15 employees or more are covered. By law, these employers are required to be flexible with your work hours and responsibilities “within reason” to help you continue to work while receiving treatment. This help may take the form of offering you flexible hours to allow you to go to appointments, letting you work out of your house or telecommuting. Employers are not required to lower their quality standards or make changes that are very costly or disruptive for other employees or customers. The Equal Employment Opportunity Commission (EEOC) decides what is considered “reasonable accommodation.” For additional details about the terms of the ADA, you may contact the U.S. Equal Opportunity Commission at (800) 669-3362.

If employers are concerned about helping workers, they may contact the Job Accommodation Network at (800) 232-9675. The network is a free service of the President’s Committee on Employment of People with Disabilities and can provide suggestions for tailoring the workplace.

If you feel you have been discriminated against, you have 180 days from the date of the action to file a complaint with the EEOC (45 days if you work for the federal government). If the agency believes you have a

“reasonable cause” to complain, it will try to work with your employer to resolve things. This may mean the use of its Alternative Dispute Resolution program, where a trained mediator works with you and your employer to resolve the difference without going to court. If mediation fails, the EEOC will take the employer to court, but going through the courts may take many years, with no guarantee of victory. At the state level, there also are agencies to help you with discrimination problems. Ask your hospital social worker about local agencies that can help you, as well.

There are several cancer support organizations that provide legal information and assistance to cancer patients and survivors. These include the National Coalition for Cancer Survivorship and the Patient Advocate Foundation.

## INSURANCE ISSUES

Paying for cancer services may be very expensive. Having your insurance coverage in place and clearly understanding the benefits of your current insurance will be very helpful as you go through the treatment process.

### To make the best sense of the financial process:

- Understand who will maintain payments on your insurance during your treatment (you or your employer). This may depend on whether you take a leave of absence or continue working.
- Keep orderly copies of all bills sent to you by hospitals, doctors and other healthcare providers. Record keeping and filing are excellent tasks to assign to loved ones who seek to support you in some way, who are good with numbers and organization.
- Keep clear records of all payments or co-payments you make, including the date, check number and amount paid. You also may find it helpful to make note on the bill itself of the check number, date and amount paid.
- Review all benefits of your current insurance for diagnostic procedures, laboratory work, doctors, hospital expenses, etc. If you find gaps in your



coverage, you may wish to consider buying additional insurance.

- If you are under the care of an HMO or PPO, be clear about which doctors or healthcare facilities you may visit directly and which require a primary care doctor's or insurer's approval before going there for treatment.

### Receiving Income during Treatment

Many workplaces offer short-term and long-term disability insurance. Depending on the insurance terms, this may allow you to take from two months up to one year away from work, while keeping 50-60% of your income. Some employers have special catastrophe/emergency funds to help employees on medical leave, such as allowing other employees to donate accumulated leave time to you. If you are likely to be away from work for over a year, you may wish to apply for Social Security Disability Insurance.

Another income source includes fundraising by friends, family or your local church organization. Some community and patient organizations offer help with rent, electricity or other needs on a one-time per year basis. Many organizations are listed in the back of this guidebook that may be helpful to you in discovering funding sources. Your social worker also may be able to direct you to sources of income support.

### Retaining Your Insurance

Retaining insurance coverage is important to helping you financially as you go through treatment and recovery. Allowing your insurance to lapse is not only expensive but also may present problems later when you try to become covered again. Many insurers have "pre-existing condition" clauses that make it difficult to become covered again, if you let your coverage stop.

If you become too ill to work or are laid off, the COBRA (Consolidated Omnibus Budget Reconciliation Act) law passed in 1986 allows ex-employees of companies with 20 or more employees to continue to participate in group insurance coverage for an additional 18 months (in special circumstances, 36 months) after you leave the company.

Spouses and dependent children also may be covered. You must accept coverage within 60 days of leaving the company. This coverage most likely will cost more than you paid as an employee. It is often less expensive than buying individual insurance.

In 1989, the Health Insurance Portability and Accountability Act (HIPAA) expanded COBRA to allow you to retain coverage under the old insurer if your new insurer does not cover a pre-existing illness like cancer. This law was passed because insurers often imposed a waiting period to start paying costs related to a pre-existing condition. If you were at your old job for one year or longer, and fewer than 63 days passed between the time your previous insurance expired and your new policy began, you should not be subject to an exclusion for a pre-existing condition. There are some exceptions, and certain states impose greater restrictions on health insurers around accepting pre-existing conditions. For questions about COBRA and HIPAA, contact the U.S. Department of Labor, Pension and Welfare Benefits Administration, Division of Technical Assistance and Inquiries, at (800) 998-7542 for publications and numbers for your regional Department of Labor field office. You also may find more information about this topic at <http://www.dol.gov/dol/pwba> (the Department of Labor website).

### If Insurance Is Denied

Sometimes people find they are denied health insurance because of a pre-existing medical condition. If you had a cancer diagnosis many years ago and are only receiving monitoring checkups, this may not be considered a pre-existing condition. Many states offer people who have been denied insurance a special program that pools their risk with others who have been denied. This is known as a "high-risk pool." Other names these programs can go by include "Medicare Supplement Plans," "Specified Disease Policies" and "Catastrophic Policies." Call your state Department of Insurance to see if such a program exists and find its cost. Your hospital social worker can help you, as well.

## OVERVIEW OF TREATMENT OPTIONS

There are several types of treatments that are used to fight cancer. The different courses of treatment recommended by your doctor(s) are a combination of “practice guidelines” – what the medical community accepts as the best tested standard of care – and doctor preference based on experience and training.

Because of the complexity of cancer, more than one type of treatment may be required to control or cure your cancer. Each treatment option has different benefits and side effects and is discussed in detail later in this guidebook’s Treatment section. On this page is a very brief highlight of the treatments that may be considered for you, depending on the type of cancer you have and its stage of development in your body.

**Surgery:** Surgeons remove cancerous tumors as well as margins around the tumor to try to remove microscopic stray cancer cells.

**Chemotherapy:** Medical oncologists prescribe one or more courses of drugs that in different combinations may kill cancer cells.

**Hormone Therapy:** Medical oncologists prescribe a course of special hormone suppressor agents that stop your own natural hormones. This is done when it is determined that your cancer is susceptible to growth from your natural hormones (estrogen-receptive breast cancer, testosterone-receptive prostate cancer, etc.).

**Radiation Therapy:** Radiation oncologists prescribe precise amounts of high energy X-rays to be delivered to the cancerous tumors and surrounding area to try to kill microscopic stray cancer cells.

**Vaccine or Biological Modifier Therapy:** Researchers today are trying to find ways to trigger the body’s own defense system to cure itself of cancer. These therapies are in clinical trial in many locations but are not yet standard in cancer care.

## GENETIC TESTING AND COUNSELING

Scientists have been able to identify certain sets of genetic mutations to be associated with particular cancers. This discovery opens up the opportunity for patients with certain cancers to receive genetic testing for specific mutations. If that mutation is found, a doctor may suggest additional counseling for the patient and his or her family members.

For instance, a woman with breast cancer might have a mutation in the BRCA1 gene, associated with a higher risk of breast cancer. Genetic counseling would discuss whether other, healthy family members should know of the mutation’s presence, as well as consider being counseled and potentially tested for the mutation to see if they are at higher risk for breast cancer.

Genetic testing of healthy people is currently controversial. In many cases, insurance companies have not yet determined what they will do with information that indicates a person has a higher lifetime risk of cancer. Another issue is that knowing there is a higher risk for cancer may cause a person to lead a more worried, unhappy life while waiting for cancer to strike. If that person never gets cancer, he or she has been worried without reason. In support of testing, a negative test result may bring great peace of mind for those worried about a genetic mutation that places them at higher risk for cancer.

Only a few cancers have had genetic mutations identified for them at present; however, new genetic mutations are being identified all the time. If you have cancer, we recommend discussing with your doctor whether genetic testing is appropriate for you.



# TREATMENT

Your cancer care team will work with you to determine the best available options for you. This section gives an overview of treatment choices and support services to help you during the treatment process and into survivorship.

## ONCOLOGY HEALTHCARE TEAM ROLES AND RESPONSIBILITIES

**Medical Oncologist:** This physician is trained in the treatment of cancer, especially with non-surgical treatments, such as chemotherapy. A medical oncologist may be the doctor in charge of your overall treatment planning and may work with surgeons or radiation oncologists to plan the overall approach to treating you. The medical oncologist will decide if there are medications or clinical trials appropriate for you and will educate you about their expected effectiveness and any potential side effects.

**Radiation Oncologist:** This physician is specifically trained in the treatment of cancer with radiation. The radiation oncologist will work with you to determine the appropriate radiation dose and specific way to deliver the radiation to your cancer to minimize radiation given to your normal, healthy cells. The doctor will instruct others in the radiation therapy department about your prescribed dose of radiation. This physician will follow up with you to check on the effectiveness of the treatment and to monitor you for any side effects.

**Medical Physicist:** A medical physicist is trained in the use of special treatment planning machinery to deliver radiation to your cancer. This specialist does quality assurance checks to make sure the treatment machine delivers radiation accurately. The medical physicist may create a specific plan for how to use the machines to deliver the radiation dose prescribed by your doctor.

**Medical Dosimetrist:** This specialist may be in charge of creating the plan for how to use the treatment machines to deliver the radiation dose prescribed by your doctor. The dosimetrist will work with the radiation oncologist and medical physicist to create the appropriate treatment plan.

**Radiation Therapists:** Registered radiation therapists work with you through the radiation therapy setup and treatment processes. They may help you understand your treatment process and get properly positioned. They also

may operate the radiation therapy equipment to deliver your prescribed dose of radiation.

**Surgeon:** The surgeon's role in cancer treatment is to review your diagnostic information and decide whether operating to remove cancerous areas from your body is a recommended treatment. If this is the case, the surgeon will then perform this operation. General surgeons operate on every part of the body, while other surgeons choose to specialize and operate only on specific parts of the body; for example, a thoracic surgeon operates on the lungs.

**Pharmacist:** A registered pharmacist works with you to review your prescriptions. The pharmacist will check to make sure the dose is appropriate and look for drug interactions with other medications you may be taking. The pharmacist advises the oncologist about any recommendations. The pharmacist also may work with you to inform you about specific medications being given to you. A pharmacist will tell you about the expected action of medications and any side effects as well as give you any warnings about interactions to avoid, such as specific over-the-counter medicines or nutritional supplements. The pharmacist also will prepare medication for you.

**Nutritionist:** A Registered Dietitian Nutritionist (RDN) will be available to help you meet your nutritional needs. This nutritionist specializing in oncology can help you keep meet your nutritional needs throughout treatment and manage certain side effects from the treatments. If you have special dietary requirements for pre-existing medical conditions or religious reasons, it is important to let your healthcare team know about these. If you are unable to eat regular meals through your mouth, the nutritionist will work with you and your doctor to help you receive adequate nutrition through other means.

**Nurses:** You will have several nurses who will work with you during your stay as an inpatient or an outpatient. Many of them will have special training in working with the needs of cancer patients. Some may have the role of helping you receive chemotherapy. Others may help your





doctor monitor your recovery from a procedure such as surgery. They may administer any prescribed medication and be available to answer questions you may have about your stay and your treatment. Nurses are present in most of the clinical areas of the hospital to help with your care.

**Social Worker:** A social worker will help with your life during and after treatment. The social worker will connect you to both emotional and financial support resources. You are encouraged to discuss your feelings and concerns with the social worker. This may help you better understand the impact of a cancer diagnosis on your life and that of your family and friends. The social worker will assess for any psychosocial needs, intervene and remove barriers.

**Chaplain:** The chaplain's role is to listen with an open heart and provide religious counsel to those who need it. The chaplain is ready to be of service to people of all faiths. If you have particular religious needs to observe during your treatment, please ask to speak to a chaplain.

## UNDERSTANDING RADIATION THERAPY

Radiation therapy is the use of high-energy X-rays for the treatment of disease, primarily cancer. Radiation can be an effective treatment for many cancers and is designed to work by preventing cancer cells from growing and multiplying. Radiation damages the tumor cells and can help prevent them from dividing. The goal is to slow or stop the growth of the tumor. In many cases, the tumor may be completely destroyed.

### First Visit/Consultation

During this time, the radiation oncologist will discuss your cancer and treatment options that are available to you. The doctor will discuss length of treatment, side effects and further tests needed. This is the time for you to ask questions. If possible, bring a family member with you to this consultation to help you understand and ask questions.

## Simulation

Simulation is the first part of the treatment planning process. The radiation oncologist uses X-ray equipment (called a CT scanner) to aid in planning your treatment. Sometimes a non-toxic dye will be given to you to outline certain internal organs. Before the simulation, the radiation therapist may place you into a special positioning device to help you hold your body still during treatment.

## Planning Marks

Planning marks allow treatment to be given precisely to the same spot each time. You will be given either small black permanent markings on your skin (about the size of a freckle) or large semi-permanent markings. These marks will aid in daily alignment. You will be able to bathe or shower normally and not be concerned about accidentally washing them off.

## Receiving Treatments

The machine used to treat your illness is designed to provide therapeutic doses of radiation. A linear accelerator will be used to deliver this radiation. During treatment, you will lie on a table, and the table will raise you up under the treatment machine. The therapist will align your body and complete imaging to ensure proper administration of therapy. Patients differ in the number of angles and sites for treatment. Your therapist will monitor your treatment from outside the room with a closed circuit television and intercom. The linear accelerator creates a buzzing sound that you will be able to hear while the radiation is delivered. It is extremely important that you do not move during your treatment.

You will be assessed weekly while receiving treatment to see how your body is responding to therapy. The nurse can answer any questions you may have at this time. Follow all home care instructions carefully and report any unusual symptoms to your healthcare team.

## Follow-up Care

It is extremely important to schedule regular exams after your treatment is finished to check the continuing effect of your treatment. This may include blood work and X-rays. Maintaining a healthy lifestyle also is part of following through after your radiation therapy is complete.

## COMMON QUESTIONS

### What Is Radiation?

Radiation is the use of high energy X-rays to treat diseases. These are therapeutic X-rays that are different from diagnostic X-rays (e.g., chest X-ray).

### What Are the Radiation Treatments Like?

You will be asked to lie on a treatment table in a certain position and hold very still. The treatment machine will move to a pre-determined position, and you will not feel or see the radiation.

### How Long Will the Treatment Take?

The treatment takes 15-30 minutes each day. The course of treatment is usually 5 days a week for 2-8 weeks.

### Who Will Give Me My Treatments?

The treatments are planned by your radiation oncologist, dosimetrist and medical physicist, and they are administered by registered radiation therapists.

### What things should I do during treatment?

Continue your normal lifestyle and daily activities. Eat well and get plenty of rest. Do not scrub off temporary marks placed on your skin until told to do so. Do not apply any salves, direct heat or cold, lotions or other self-remedies to the skin area being treated unless recommended by your healthcare team.

## RADIATION ONCOLOGY TECHNIQUES AVAILABLE AT PHELPS HEALTH

### IMRT

IMRT— Intensity-Modulated Radiation Therapy — is a state-of-the-art cancer treatment method that delivers high doses of radiation directly to cancer cells in a very targeted way, much more precisely than is possible with conventional radiotherapy.

SmartBeam IMRT involves varying (or modulating) the intensity of the radiation dose. It can deliver higher radiation doses directly to cancer cells while sparing more of the surrounding healthy tissue. It uses computer-generated images to plan and then deliver



more tightly focused radiation beams to cancerous tumors than is possible with conventional radiotherapy. With this capability, therapists can deliver a precise radiation dose that conforms to the shape of the tumor, while significantly reducing the amount of radiation to surrounding healthy tissues. Consequently, the technique can increase the rate of tumor control while significantly reducing adverse side effects.

IMRT is the most precise form of radiation therapy available. It allows physicians to escalate the radiation dose to cancer cells, and in some cases, even more precisely to specific metabolically active regions within a tumor, while keeping the dose to surrounding tissues as low as possible. An analogy might be painting with a paintbrush as compared to using an airbrush and masking tape to protect outlying areas. The airbrush allows you to deposit variable amounts of paint in a highly controlled fashion. IMRT does something similar with radiation.

A medical linear accelerator, equipped with a special device called a multileaf collimator that shapes the radiation beam, delivers the radiation in accordance

with the treatment plan. The equipment can be rotated around the patient to send radiation beams from the most favorable angles for giving the tumor a high dose while preserving important healthy tissues.

### IGRT

IGRT — Image-Guided RadioTherapy — refers to the use of sophisticated imaging technologies to guide the delivery of precise forms of radiation therapy. Tumors can move during treatment (usually due to patient respiration) and between treatments (usually due to day-to-day variations in patient setup). Dynamic Targeting IGRT from Varian Medical Systems offers clinicians advanced imaging techniques to verify patient position and tumor position at the time of treatment. Knowing exactly where the tumor is allows clinicians to reduce the volume of tissue irradiated, targeting only the tumor and sparing the surrounding normal tissue. Irradiating less normal tissue reduces the toxicity of radiotherapy, improving the patient's quality of life. This may make it possible to deliver higher radiation doses to the tumor and thereby increase the likelihood of local tumor control. Through more precise targeting of the beam,

dosage levels can be increased and target volumes (the three-dimensional areas to receive treatment) can be reduced — so tumors get a higher dose of radiation and healthy surrounding tissues get very little. Higher doses have been shown to enhance treatment effectiveness. And better targeting reduces the possible side effects of radiotherapy.

IMRT and IGRT are being used to treat tumors in organs including the brain, breast, head and neck, liver, lung, nasopharynx, pancreas, prostate and uterus.

### OSMS

OSMS – Optical Surface Monitoring System – is a newer technology that is becoming widely used to monitor a patient’s positioning before and during treatment to ensure pinpoint accuracy. Special cameras render a real-time 3D image of the body and compare it to the baseline CT imaging that was performed for planning purposes before treatment. Directions are then provided for the therapist to position the patient for treatment and monitor movement during treatment. This advanced system also is able to link to the treatment delivery system to automatically pause radiation, if necessary.

### DIBH

Deep Inspiration Breath Hold (DIBH) is used in conjunction with OSMS. DIBH is an effective treatment technique to limit radiation exposure to the heart and lungs by having the patients hold their breath. This is particularly useful for treating patients with left-sided breast cancer and tumors in the chest and abdomen.

### RapidArc

RapidArc™ radiotherapy technology is a new form of image-guided, intensity-modulated radiation therapy (IMRT). Image guidance improves tumor targeting, and IMRT shapes the radiation dose so that it conforms closely to the three-dimensional shape of the tumor. This means more dose to the tumor and less to surrounding healthy tissue.

RapidArc quickly delivers a complete IMRT treatment with a single rotation of the treatment machine around the patient. The entire tumor volume receives the radiation dose during this one revolution of the machine.

RapidArc involves varying (or modulating) the intensity of the radiation (in this case, high-energy X-rays) being used as therapy for cancer.

To administer a RapidArc treatment, therapists use computer-generated images to plan and then deliver tightly focused radiation beams to cancerous tumors. Using RapidArc technology, clinicians can deliver a precise radiation dose that conforms to the shape of the tumor, while limiting the amount of radiation that reaches surrounding healthy tissues.

RapidArc is an extremely fast and precise form of radiation therapy. It allows clinicians to quickly and accurately deliver a dose to cancer cells while keeping the dose to surrounding tissues as low as possible.

Faster treatments are not only more comfortable, they also may be more accurate. Since a patient will spend less time holding still, it will be easier to avoid movements that could compromise the accuracy of the treatment. RapidArc delivers treatments two to eight times faster than earlier forms of radiotherapy.

## UNDERSTANDING CHEMOTHERAPY

Chemotherapy is the use of medications to treat cancer. Depending on the type of cancer and its stage, the four main goals of chemotherapy are: to cure cancer, to keep cancer from spreading, to slow the growth of cancer and to relieve cancer symptoms.

Chemotherapy helps destroy cancer cells by stopping them from growing and multiplying. It may be used along with radiation therapy, surgery or both. More than one chemotherapy drug may be given at a time because some drugs work better together than alone.

Your doctor will recommend the medications and dosage schedule appropriate for you. The decision depends on the kind of cancer you have, whether or not it has spread (metastasized) from its original site, the extent of its growth and your general health.



### How Chemotherapy Is Given

Chemotherapy can be given in different ways. Some common methods include intravenous, oral, intramuscular and intrathecal.

The intravenous (IV) route is a very common way to put medicine directly into a vein. A small needle is inserted into one of the veins in the lower arm. Some discomfort may be felt during insertion of the needle into the skin. The chemotherapy flows through the needle and plastic tube (catheter) into the bloodstream. Sometimes a syringe is used to “push” the chemotherapy through the tubing. This is called an IV push medication. When you receive chemotherapy through an IV, it is very important to tell your nurse right away if there is any redness, burning or discomfort in the IV area.

A more permanent type of catheter may be recommended to avoid repeated painful needle sticks into the vein. These permanent catheters are called central venous catheters or implanted ports. Central venous catheters are surgically inserted into one of the large central veins in the chest and stay in place until the therapy is completed. Chemotherapy, blood and IV fluids can be given through this catheter, and blood for lab tests

can be drawn from this site. The tube will be capped and covered by a dressing, and your nurse will teach you how to care for the catheter to avoid infection.

An implanted port is round in shape and usually surgically inserted under the skin surface on the chest wall between the neck and shoulder. To use the port, the nurse will insert a needle through the top skin surface to access the port. Chemotherapy, blood and IV fluids can be given through this port, and blood can be drawn from the port. Home care is usually required only at initial insertion.

#### Other chemotherapy delivery methods include:

- Oral: includes pills, capsules or liquids taken by mouth.
- Intramuscular: an injection into the muscle.
- Intrathecal: Certain types of cancer have a tendency to spread to the central nervous system. To prevent this, doctors may inject a chemotherapy medication into the spinal fluid through a spinal tap.
- Subcutaneous: An injection into the space between the skin and muscle that does not enter the muscle layer.



### Treatment Length and Frequency

You may be treated in your doctor's office, in a clinic in the DDCI, receive pills to take on a specific schedule at home or receive drugs at home via an implanted pump. Your dosage schedule may last from a few weeks to a year, with a varying cycle frequency (once a week, once a month or other intervals).

Take reading materials and/or an electric device (Wi-Fi is available) to help pass the time while you are receiving treatment at the doctor's office or as an outpatient at the DDCI. Treatments are followed by rest cycles to give your body time to build healthy new cells and regain strength.

Your doctor may provide a list of instructions for care between chemotherapy cycles. Follow them carefully and stay focused on having a good outcome from treatment.

## COMMON QUESTIONS

### Will I Become Nauseated from Chemotherapy?

Some, but not all, chemotherapy agents may cause nausea and vomiting if you do not take any preventive measures. Your healthcare team knows which agents are likely to cause nausea and vomiting, and you may be prescribed additional anti-nausea medications for you to take before, during or after a chemotherapy treatment to help minimize this side effect.

### Will I Lose My Hair With Chemotherapy?

Some treatments may cause loss of hair while you are taking them, not only on your head, but also in other areas of your body. Generally your hair will grow back after treatment. Your doctor knows which treatments are likely to cause hair loss.

### Why Do I Have to Take Chemotherapy Over Multiple Courses?

Chemotherapy is usually delivered systemically, so that both your healthy and cancerous tissues are exposed to the drug. Chemotherapy can be used this way because cancer cells are more vulnerable to treatment than healthy cells. However, your body's healthy tissues need time to recover their strength. Typically, you will

receive an initial course of treatment, which will let the doctor know if the agent is effective against your cancer. Then you will receive additional courses as necessary, depending on your overall health, to try and destroy any remaining cancer cells in your body.

## UNDERSTANDING IMMUNOTHERAPY

The immune system is made of white blood cells, organs and tissues of the lymph system. It helps your body fight infections. Immunotherapy is a treatment that helps your immune system fight cancer. One reason that cancer cells thrive is because they are able to hide from your immune system. Some immunotherapy treatments can identify cancer cells so it is easier for the immune system to find and eliminate them. Others boost your immune system to fight against your cancer. There are many different types of immunotherapy. The type of cancer you have determines if immunotherapy is appropriate for you.

### How Immunotherapy Is Given

Immunotherapy may be given in different ways. These include intravenous (IV), oral, topical and intravesical.

### How Often Immunotherapy

#### Treatment Is Given

How often and how long a person receives immunotherapy depends on the type of cancer and how advanced it is, the type of immunotherapy given and how the person's body reacts to treatment. Treatments may be every day, week or month. Some are given in cycles. A cycle is a period of treatment followed by a period of rest. The rest period gives the body time to recuperate and respond to immunotherapy.

### How Immunotherapy Makes People Feel

Immunotherapy can affect people in different ways. The current health status before treatment, the cancer type and stage, specific therapy and dose are all factors for how the immunotherapy will affect the patient. The side effects of immunotherapy include fatigue, fever, rash and decrease in blood pressure. All of this information will be reviewed by the provider prior to starting immunotherapy.

## UNDERSTANDING SURGERY

Surgery is often used as a treatment for cancer. It may be done as a first-line treatment, or your doctor may recommend surgery after chemotherapy and/or radiation therapy has reduced the size of any operable tumors. Some tumors are considered inoperable, which means that the doctor feels the cancer has spread beyond the initial tumor site and surgery will not capture all of the cancer in your body. In this case, other non-surgical treatments may be appropriate.

Learning more about the operation your doctor recommends will help you make better decisions about your healthcare. **Questions you may wish to discuss with your doctor before surgery include:**

- What operation are you recommending? Make sure you understand what is going to be repaired or removed, and ask your doctor to draw any pictures or diagrams if you need help understanding.
  - Why do I need this operation? The operation may be to relieve pain, to reduce a symptom, improve a body function or to remove cancerous or benign (non-cancerous) tumors.
  - What are the benefits of having the operation? Ask whether additional operations will be needed later and what effect the doctor expects the surgery to have on treating your cancer.
  - Are there alternatives to this type of surgery? You want to feel comfortable that this operation is what you need now to treat your cancer. Alternatives may include other types of surgery as well as medicines and radiation therapy, or even watchful waiting.
  - What are the risks of having the operation? You will want to understand these risks and compare them to the benefits. Risks may include complications around the time of surgery, such as a reaction to anesthesia, an infection, excessive bleeding or impact on other medical conditions you may already have. Other risks to understand are side effects, such as swelling and soreness at the incision site, and long-term effects from the removal of any body parts such as lymph nodes or portions of a major organ.
  - What is my prognosis if I do not have this operation?
- Find out what the impact of delaying or not having the operation may be.
- How long can I reasonably wait to make a decision about treatment without jeopardizing the treatment's effectiveness?
  - What about getting a second opinion? A second opinion can be a good way to feel sure that you are getting the appropriate treatment for your cancer. Your insurance plan may even require you to get a second opinion. Check to see if your insurance will pay for one if it is not required. If you get a second opinion, be sure to bring all of your records so that the second doctor does not need to repeat tests. You can learn about specialists for second opinions from your surgeon, your primary care doctor, the local medical society or your insurance. Medicare patients may receive information by calling (800) 633-4227.
  - What has been your experience with this operation? You wish to choose a surgeon who has experience and training in your recommended surgery. You may ask the surgeon directly about his or her success rate and rate of complications, or you may inquire through your primary care doctor or even your insurer. Some surgeons have the letters, FACS, after their names. This means the surgeon is a Fellow of the American College of Surgeons and has gone through an exam and review by other surgeons within the specialty.
  - Where will the operation be done? Some doctors may operate at more than one hospital. You may inquire about the success rate for your particular surgery at each hospital and may visit the hospitals to see where you feel more comfortable. Ask if your surgery will be conducted on an inpatient (overnight stay) or outpatient (same day) basis.
  - What kind of anesthesia will I need? Anesthesia is used to prevent unnecessary pain. It may be local (around the incision site, as for a dental cavity), regional (numbing that region of the body around the site, as in an epidural), or general (affecting your whole body, usually making you unconscious). The length of time the numb sensation will last depends on how it is administered.
  - How long will it take me to recover? Your surgeon

can tell you the average time patients take to recover from the operation. Ask about what the steps to recovery should look and feel like, so you know what to expect as far as monitoring complications and side effects from surgery.

- Will I need special help at home after the surgery? Find out if there are restrictions on your activity at home, and whether you should have help, either from a loved one or from a professional. Find out about any special supplies or equipment you might need at home.
- How much will the operation cost? Ask your insurer how much of the operation's cost is covered by them, and how much of the cost is your responsibility. If you have concerns about meeting your financial responsibility, speak to the financial staff at the hospital and your doctor about payment plans to fit your needs. Remember that there are often many different sets of charges associated with an operation, including diagnostic tests, pharmacy, medical supplies, room charges and staff fees as well as fees for the surgeon and the anesthesiologist.

## DIAGNOSTIC IMAGING

This section discusses the most common diagnostic equipment used to determine the location and specific type of disease you may have. Each test provides different information about your body to your doctor, so you may be asked to have more than one of these tests. Remember...it is important to be your own best health advocate. Follow all instructions you are given for care before your diagnostic appointment. Report any unusual symptoms, or if you are or may be pregnant, to your technologist when you check in for your test.

### Bone Scan (Nuclear Medicine)

A bone scan is used to see if the disease has entered your bones. It is similar to an X-ray in that it uses radiation to look at the condition of your bones. However, in this case, you take radioactive material (radionuclide) internally, usually via injection. The radionuclide travels in your blood and settles in areas where the bone is building or breaking down. This bone activity could be from cancer,

arthritis or a recent bone fracture. The radionuclide sends out a weak radiation signal that is read by a machine called a gamma camera.

You should feel no discomfort from the radionuclide or the scan. The radioactivity of this material lasts for a very short period in the body and actually gives you no more radiation than a typical external X-ray, like a chest X-ray. This test is an important way to get information about whether the disease has developed in the bones in your body much earlier than a normal X-ray would show a problem. The scan itself is done two to three hours after you take the radionuclide and takes about 60 minutes. After your injection, you will be asked to drink fluids and empty your bladder during the waiting period to flush the material from your urine and make the image of your bones clearer.

### Positron Emission Tomography (PET) Scan

A PET scan is generally used in combination with an MRI or CT scan. It uses a tracer material that sends a strong signal out from areas of your body that may be abnormal. You will be asked to fast for anywhere from four to six hours before the scan to allow your body to absorb the tracer effectively. Your glucose level will be measured before the scan. To take the scan, you will be injected with a small amount of radioactive (radiolabeled) tracer material.

You should feel no discomfort from the tracer or the scan. You will be asked to rest for one hour before the injection. You then will be asked to lie on a table that slides into the PET/CT scanner. It is important to remain very still during the scan. You will not feel the scan, but you might hear some noise as the scanner moves. The radioactivity of the tracer disappears quickly, and you can be with your loved ones after the scan.

### Computed Axial Tomography Scan (CT or CAT)

A CT or CAT scan uses low-energy X-rays and computers to create a cross-sectional image of your body. It provides much more information than a basic X-ray. A CT scan is performed while you lie on a long table that slides into

a large circular opening in the imaging machine. The scanner will rotate around you, emitting X-rays and a buzzing noise. It is important to remain very still during the procedure. Sometimes an injection of a contrast agent is given to help make the image clearer for the doctor. You will be able to speak to the technologist while you are in the machine. The scan may take 15-30 minutes. Alert your doctor if you are pregnant or allergic to iodine.

### Magnetic Resonance Imaging (MRI)

An MRI machine creates an image of the body using a large magnet. You will lie on a table that slides into the MRI machine. You will not feel the magnetic field, but you will hear some noise. It is important to remain very still during the scan. The procedure takes typically from 45-60 minutes, and you will be able to speak to the MRI technologist the entire time. **During this test, do not wear:**

- Jewelry
- Metal objects
- Eyeglasses
- Dental pieces
- Makeup

Before the procedure, let the technologist know if you have a pacemaker, have had heart valves replaced or have any metal in your body, including surgical staples, metal fillings or permanent makeup. Also let staff know if you become claustrophobic (there is little clearance inside the MRI machine), have had a bullet wound or worked with metal (metal shavings risk).

### Ultrasound

An ultrasound machine uses high-frequency sound waves and a computer to create pictures of your body. A special gel is put on the skin where you are to be scanned to help conduct the sound. Then, the technologist guides a sensor wand across the skin that sends the sound waves throughout the area. Ultrasound may be used externally or internally in the rectal or vaginal areas, depending on the area to be scanned. You will not feel or hear the high-frequency sounds the ultrasound machine makes. The images appear on a TV screen and are recorded. Depending on the area to be scanned, you may be asked to drink lots of water and then wait to urinate until after the exam; this helps to improve the image.

## UNDERSTANDING TUMOR MARKERS

Your blood, urine or body tissues may be tested for certain substances called tumor markers, which may indicate the presence of certain cancers in your body. We do not yet have tumor markers for every cancer but are discovering more every day. **Tumor markers have many uses:**

- Screening for the presence of cancer
- Making a diagnosis of cancer
- Determining the status of the cancer
- Evaluating the success of surgery, radiation or chemotherapy in controlling cancer
- Monitoring the health of a patient in remission (no active cancer seen)

Tumor markers are either sent into the blood by the tumor itself, or by the body in response to the tumor. A tumor marker test, in combination with other diagnostic tools, will help guide your doctor in the appropriate treatment for you. These tests are typically given before treatment. Your doctor will then set a schedule to test you regularly in the months after treatment to check if your levels have dropped in response to treatment and remained low.

Tumor markers are not always predictive of cancer because they can be present in many benign (non-cancerous) conditions. Also, not every person with a cancer will have that cancer's tumor marker, especially in the early stages. Given these issues, at this time the majority of tumor markers are not useful as screening tools to catch cancer in the early stages. Information follows about commonly used tumor markers. This is not an all-inclusive list. Your physician will provide you with information specific to your cancer.

### PSA and PAP

Prostate Specific Antigen (PSA) and Prostatic Acid Phosphatase (PAP) are markers normally present in men's blood in small amounts. They can be elevated in the presence of prostate cancer. An elevated PSA may also be a signal of other non-cancerous diseases such as benign prostatic hyperplasia (BPH) or prostatitis. These are very common conditions in men as they get older, so doctors use other tests besides the PSA to check for

cancer. A decrease in PSA is a signal that prostate cancer therapy may have been successful. PSA re-elevation is a potential, but not certain, sign of recurrence. If you have an elevated PSA score, your doctor will do a digital rectal exam and may order an ultrasound or biopsy of the prostate.

### **CA-125**

Carbohydrate Antigen 125 (CA-125) is at elevated levels in women with ovarian cancer. It is sometimes elevated in the presence of other cancers. Its most common use today is to check for success in treating ovarian cancer and to monitor for ovarian cancer's potential recurrence. CA-125 is not useful as a screening test because of the high number of women with ovarian cancer who do not have this marker. Many non-cancerous conditions elevate this marker, such as pelvic inflammatory disease, endometriosis and liver disease.

### **CA 15-3 and CA 27-29**

CA 15-3 and CA 27-29 are markers useful in following the course of breast cancer and its response to treatment. They are not used as screening tests because they are not detectable in early-stage breast cancer.

### **CA 19-9**

CA 19-9 marker level is commonly used as a check for the spread of pancreatic cancer. It also may be elevated in patients with colorectal, stomach and bile duct cancers. There are non-cancerous conditions such as gallstones and cirrhosis that can elevate this marker.

### **CEA**

Carcinoembryonic antigen (CEA) marker is normally present in small amounts. It can be elevated in the blood of patients with a wide variety of cancers. CEA is not used as a screening test because it is so widely present and can be elevated with chronic diseases such as bronchitis and irritable bowel syndrome. CEA is used today as a marker for the success of therapy for colorectal cancer and to test for recurrence of colorectal cancer.

## **COMMON QUESTIONS**

### **If I Have a High Level of a Tumor Marker Like PSA or CEA, Do I Have Cancer?**

No, a high level of a tumor marker does not automatically mean you have cancer. Other diseases can cause high marker levels, so your doctor will order more tests to determine the meaning of your tumor marker test results.

### **Will the Tumor Marker Level Change with Treatment?**

If your treatment is effective in controlling the cancer, you should expect to see the level of your tumor marker decrease significantly.

### **Why Cannot All Tumor Markers Be Used to Catch Cancer in the Early Stages?**

Not all cancers create tumor markers in the blood in the early stages. Many cancers share the same tumor marker, so it is hard to connect a particular marker to a type of cancer. Non-cancerous conditions also can elevate tumor markers.





## CLINICAL TRIALS

As you and your doctor consider your options for treatment, you may wish to consider participating in a clinical trial. Clinical trials are research studies designed to find better ways to treat cancer and help cancer patients. Clinical trials test many types of treatment such as new drugs, new approaches to surgery or radiation therapy, new combinations of treatments or new methods, such as gene therapy.

A clinical trial is one of the final stages of a long and careful cancer research process. The search for new treatments begins in the laboratory, where scientists first develop and test new ideas. If an approach seems promising, the next step may be testing a treatment in animals to see how it affects cancer in a living being and whether it has harmful effects. Of course, treatments that work well in the lab or in animals do not always work well in people. Studies are done with cancer patients to find out whether promising treatments are safe and effective.

### Why Are Clinical Trials Important?

Clinical trials are important in two ways. First, cancer affects us all, whether we have it, care about someone who does or worry about getting it in the future. Clinical trials contribute to knowledge and progress against cancer. If a new treatment proves effective in a study, it may become a new standard treatment that can help many patients. Many of today's most effective standard treatments are based on previous study results. Examples include treatments for breast, colon, rectal and childhood cancers. Clinical trials also may answer important scientific questions and suggest future research directions. Because of progress made through clinical trials, many people treated for cancer are now living longer.

Second, the patients who take part in a trial may be helped personally by the treatment(s) they receive. They get up-to-date care from cancer experts, and they receive either a new treatment being tested or the best available standard treatment for their cancer. Of course, there is no guarantee that a new treatment being tested or a standard treatment will produce good results. New treatments also may have unknown risks. But if a new treatment proves effective or more effective than standard treatment, study patients who receive it may

be among the first to benefit. Some patients receive only standard treatment and benefit from it.

In the past, clinical trials were sometimes seen as a last resort for people who had no other treatment choices. Today, patients with common cancers often choose to receive their first treatment in a clinical trial.

### What Happens in a Clinical Trial?

In a clinical trial, patients receive treatment, and doctors carry out research on how the treatment affects the patients. While clinical trials have risks for the people who take part, each study also takes steps to protect patients.

When you take part in a clinical trial, you receive your treatment in a cancer center, hospital, clinic and/or doctor's office. Doctors, nurses, social workers and other health professionals may be part of your treatment team. They will follow your progress closely. You may have more tests and doctor visits than you would if you were not taking part in a study. You will follow a treatment plan your doctor prescribes, and you also may have other responsibilities, such as keeping a log or filling out forms about your health. Some studies continue to check on patients even after their treatment is over.

### How Is the Research Carried Out? How Are Patients Protected?

In clinical trials, both research concerns and patient well-being are very important. To help protect patients and produce sound results, research with people is carried out according to strict scientific and ethical principles. These include:

1. Each clinical trial has a protocol (action plan) that explains how it will work. The study's investigator, usually a doctor, prepares the protocol for the study. This plan explains what will be done in the study and why. It outlines how many people will take part in the study, what medical tests they will receive and how often, and the treatment plan. The same protocol is used by each doctor who takes part in the trial.

For patient safety, each protocol must be approved by the organization that sponsors the study (such as

the National Cancer Institute) and the institutional review board (IRB) at each hospital or other study site. This board, which includes consumers, clergy and health professionals, reviews the protocol to try to be sure that the research will not expose patients to extreme or unethical risks.

2. Each study enrolls people who are alike in key ways. The study's protocol describes the characteristics that all patients in the study must have. Called eligibility criteria, these guidelines differ from study to study, depending on the research purpose. They may include age, gender, the type and stage of cancer, and whether cancer patients who have had prior cancer treatment or who have other health problems can take part.

Using eligibility criteria is an important principle of medical research that helps produce reliable results. During a study, these criteria help protect patient safety, so that people who are likely to be harmed by study drugs or other treatments are not exposed to the risk. After results from the study are in, these criteria also help doctors know which patient groups will benefit if the new treatment being studied is proven to work. For instance, a new treatment may work for one type of cancer but not for another, or it may be more effective for men than women.

3. Cancer clinical trials include research at three different phases. Each phase answers different questions about the new treatment:

**Phase I trials** are the first step in testing a new treatment in humans. In these studies, researchers look for the best way to give a new treatment (e.g., by mouth, IV drip or injection? how many times a day?). They also try to find out if and how the treatment can be given safely (e.g., best dose?); and they watch for any harmful side effects. Because less is known about the possible risks and benefits in Phase I, these studies usually include only a limited number of patients who would not be helped by other known treatments.

**Phase II trials** focus on learning whether the new treatment has an anticancer effect (e.g., Does it

shrink a tumor? Improve blood test results?). As in Phase I, only a small number of people take part because of the risks and unknowns involved.

**Phase III trials** compare the results of people taking the new treatment with results of people taking standard treatment to determine which group has better survival rates and fewer side effects. In most cases, studies move into Phase III testing only after a treatment shows promise in Phases I and II. Phase III trials may include hundreds of people around the country.

4. In Phase III trials, people are assigned at random to a group to receive either the new treatment (the treatment group) or the standard treatment (the control group). This method, called randomization, helps avoid having the study's results affected by human choices or other factors not related to the treatments being tested.

In some studies, researchers do not tell the patient whether he or she is in the treatment or control group (called a single-blind study). This approach is another way to avoid bias because when people know what drug they are taking, it might change the way they react. For instance, patients who knew they were taking the new treatment might expect it to work better and report hopeful signs because they want to believe they are getting well. This could bias the study by making results look better than they really are. Some studies are done as double-blind studies, in which neither the doctor nor the patient knows until the study is over to which group each patient belongs. This is done to avoid bias on the part of the observing doctor as well as the patient.

### Why Do Phase III Clinical Trials Compare Treatment Groups?

Comparing similar groups of people taking different treatments for the same type of cancer is another way to make sure that study results are real and caused by the treatment rather than by chance or other factors. Comparing treatments with each other often shows clearly which one is more effective or has fewer side effects.

Another reason Phase III trials compare the new treatment with standard treatment is so that no one in a study is left without any treatment when standard treatment is available, which would be unethical. When no standard treatment exists for a cancer, some studies compare a new treatment with a placebo (a look-alike pill that contains no active drug). However, you will be told if this is a possibility before you decide whether to take part in a study.

### Paying for Clinical Trials

As you consider enrolling in a clinical trial, you will face the critical issue of how to cover the costs of care. Even if you have health insurance, your coverage may not include some or all of the patient care costs associated with a clinical trial. This is because some health plans define clinical trials as “experimental” or “investigational” procedures. In 2000, Medicare began covering beneficiaries’ patient care costs in clinical trials. Up-to-date information about what Medicare will cover can be found by writing: Clinical Trial Policy, Office of Clinical Standards and Quality, Health Care Financing Administration, 7500 Security Boulevard, S3-02-01, Baltimore, MD 21244 or online at the Centers for Medicare and Medicaid (formerly the Health Care Financing Administration) website at <https://www.cms.gov/>

### Your Doctor Can Tell You More

If you have any questions about how clinical trials work, ask your doctor, nurse or other health professional.

## UNDERSTANDING HEALTHCARE RESEARCH

You may hear about healthcare research through the nightly news, your daily newspaper, on the Internet or from a concerned friend. **There are four main types of studies around cancer’s prevention and cure:**

- Laboratory experiments are used to find the cause of cancer or discover the effectiveness of a drug or

treatment. They are usually conducted on animals or on cells or tissue.

- Clinical trials test to make sure that a treatment is the true source of the improvement seen in the laboratory and not some other influences. Participants in trials are randomly selected to receive either the treatment being studied or the current standard of care. The groups are monitored and the results compared to determine the treatment’s effectiveness.
- Epidemiological research studies look at the natural course of a disease in various groups of people with certain characteristics, such as ethnic background or exercise habits. These types of studies have shown that smokers, for instance, have a higher risk of lung cancer.
- Outcomes research is also called “evidence-based medicine.” These studies look at the results of treatments to see if certain types of patients, or if patients in certain situations, respond better to treatment. The results are sometimes pulled into practice guidelines when the studies show a strong result for that patient group. Your doctor may use these guidelines to help determine your treatment options. Many of these guidelines are available on the Internet. The National Guideline Clearinghouse™, sponsored by the federal Agency for Healthcare Research and Quality, the American Medical Association and the American Association of Health Plans Foundation, has hundreds of these evidence-based guidelines at <http://www.guideline.gov>. The National Cancer Institute’s website, <https://www.cancer.gov>, also has many guidelines for cancer treatment.

## SURVIVORSHIP

*(From cancer patient to cancer survivor)*

The end of your cancer treatment can be both exciting and stressful. You are excited because treatments are over but stressed because of the fear of the cancer coming back. These feelings are normal for anyone who



has had cancer. Survivorship is not just about long-term survival; it is also about your quality of health from this point on.

Survivorship is about living with, living through and living beyond cancer. **In establishing your “new normal,” there are many things to consider in your follow-up care:**

- Physical Health
- Emotional Health
- Lifestyle Changes

### Physical Health

#### Follow-up Appointments:

When cancer is no longer detectable in your body, you are considered to be in remission, or “no evidence of disease.” Doctors do not use the term “cured” until there is no evidence of cancer for a number of years. The time frame for your cancer to be considered “cured” depends on the type of cancer you had. After treatment ends, you will need to see your doctor for follow-up. These visits may include physical exams and blood tests, which can help tell if the cancer has come back. Other tests, like chest X-rays, CT scans or MRIs, also may be needed.

**It is very important that you keep up your scheduled follow-up appointments.** A schedule of your follow-up appointments is in your survivor care plan and your patient portal.

During your first visit, you should have received information on how to sign up for the DDCI patient portal, which offers you secure, online access to oncology healthcare information anytime and anywhere. Through

the DDCI patient portal, you can view your appointments and test results, complete healthcare assessments, access educational materials and view contact information for your care team. For more information or to login, visit [phelpshealth.org](https://phelpshealth.org).

#### Signs of recurrence to watch for:

An important thing to know to improve your health and decrease your anxiety is to know what symptoms of recurrence to watch for. Your care team will tell you what to watch for and will ask you at each follow-up visit. Be sure and call your doctor about any changes you notice or tell them at each visit – even if you think it is nothing.

**Management of any long-term side effects you may have from treatment:** Many survivors have long-term side effects from cancer treatments. These side effects vary depending on your cancer and your treatments. Some might include: skin changes, lymphedema, neuropathy (pain in feet, hands or legs), fatigue and more. Be sure to talk with your doctor about what is normal and if there is anything to do that can help. Cancer rehabilitation also is available.

### Emotional Health

Cancer often creates a state of crisis with fear and uncertainty. Cancer-related fears can be managed.

Many cancer survivors find that continuing to participate in support groups after treatment is helpful when making the adjustment to surviving cancer. Some survivors find

it rewarding to volunteer with organizations that help new cancer patients. Some find they want to encourage others to do their proper cancer screenings. Yet others wish to completely forget their treatment experiences and try and return their lives to normal as much as possible. No one of these coping strategies is right.

Phelps Health has cancer support groups available. A general cancer support group for patients and families meets every Wednesday at 5:00 PM in the Shirley Day Conference Center at the DDCI. A breast cancer support group meets the second Wednesday of every month at 2:00 PM also in the Shirley Day Conference Center at the DDCI. Also, be sure to talk to someone if you experience depression, anger or fear that affects your everyday life. Counseling is available and can help – talk to someone. All your caregivers are listed on your survivorship care plan and on the patient portal. Phelps Health has a social worker who help you find the resources you need. Call (573) 458-8339.

### Healthy Living

Having cancer and dealing with treatment can take a lot of your time. But now you have time to look at your life in new ways. Now is a great time to think about how to improve your overall health and feel better.

#### Ways to improve your health:

- Quitting smoking is the single most important thing you can do for your health and the health of your family. Call the American Cancer Society at (800) 227-2345 for information and support.
- Eating healthy after cancer treatments can be difficult. Phelps Health has an oncology nutritionist who can meet with you. Call (573) 458-8337 to get more information.
- Exercise

Cancer rehabilitation services are available at (573) 458-7140 to help you get started.

Make sure you received your survivorship care plan as you finished your treatments. **This plan consists of:**

1. Patient instructions of how to sign in to the

patient portal are usually given at your first appointment

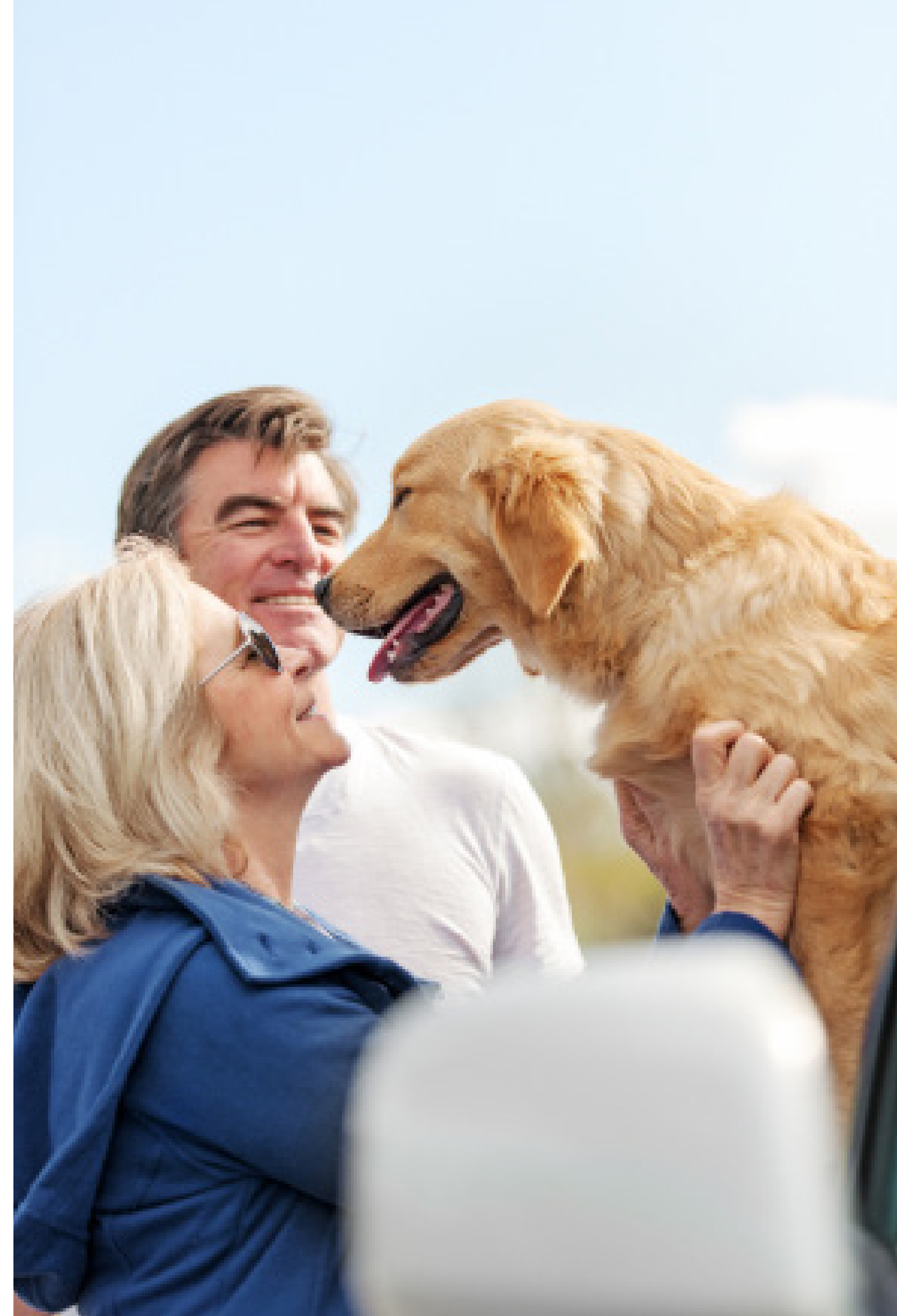
2. Treatment summary (Treatments received through the DDCI)
3. Follow-up plan, specific to your cancer, with target dates for follow-up
4. Care team names, addresses, phone numbers and emails

Your healthcare team at Phelps Health and the DDCI is here for you for any needs you may have. Be sure to follow up and call us whenever you need us.

### Here's to health and hope!

*Information compiled from the American Cancer Society <http://www.cancer.org/index> and the National Coalition for Cancer Survivorship <http://www.canceradvocacy.org/>.*





# SIDE EFFECT MANAGEMENT

During your course of treatment for cancer, you may experience symptoms and side effects. This section offers some tips and techniques for coping while you undergo treatment.

## SIGNS AND SYMPTOMS REQUIRING IMMEDIATE CARE

If you have any of the following symptoms during your course of treatment for cancer, you need to be evaluated by a healthcare professional to see if your treatment needs alteration. Proactive and early treatment of symptoms may prevent serious complications to your health and help you get the maximum benefit from your cancer treatment. **Symptoms to report immediately (Call 911, go to the nearest emergency department or call your doctor's office, even if it is a weekend) include:**

- Fever above 101 degrees F
- Shaking chills
- Uncontrolled severe pain
- Large amounts of bleeding

Symptoms to report to your doctor within 48 hours:

- A sore that is red, swollen or not healing as usual
- Severe cough or a cough producing yellow sputum
- Sore throat
- Bruising
- Blood in urine or bowel movements
- Bleeding gums or nose
- Mouth sores or white patches in mouth
- Vomiting lasting longer than 24 hours
- Diarrhea (three or more liquid stools per day) lasting longer than 48 hours
- Constipation (no bowel movement in three days)
- Pain or burning when urinating

These symptoms may be caused by a reduced white blood cell count (neutropenia), which has allowed an infection to develop. They also may be a result of treatment reducing your healthy tissue's ability to regenerate itself quickly. Your healthcare professionals can decide if you need medicine, such as an antibiotic or special salve, to fight your symptoms. They also can help decide if your treatment schedule requires changing and may provide relief from your discomfort. Additional ideas in reducing your symptoms and feeling better during treatment are listed in this section of the guidebook.

Make sure you find out from your healthcare team the signs and symptoms specific to your care that require medical attention.

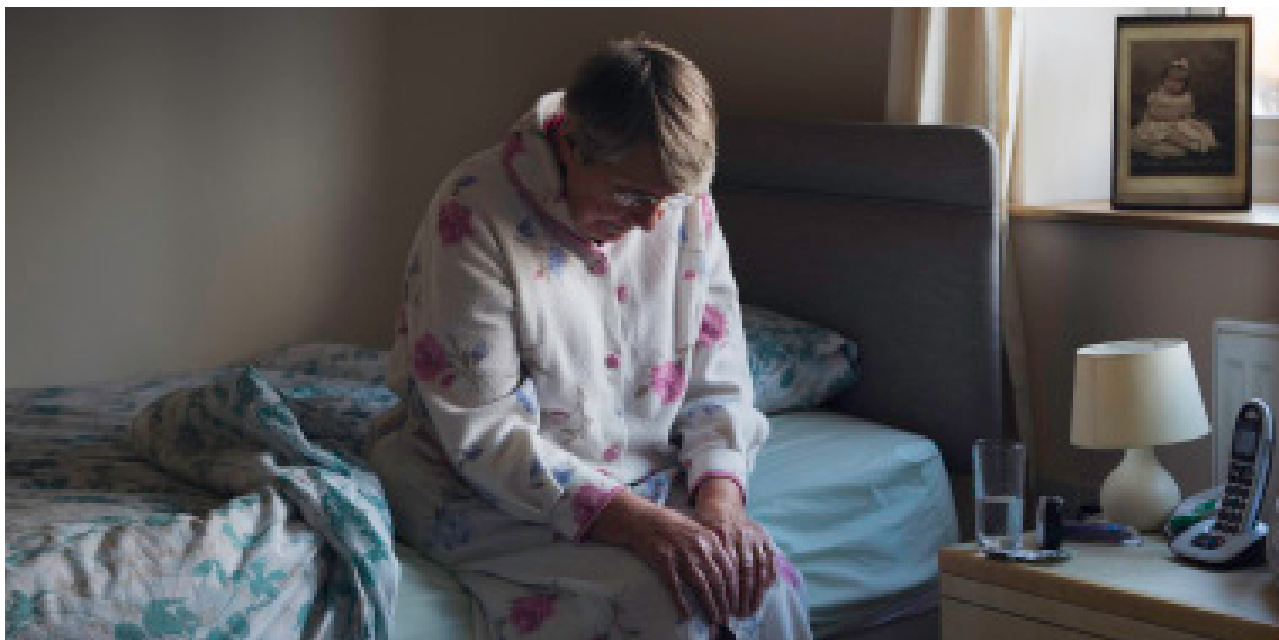
## Side Effect Management

Because radiation therapy and chemotherapy treatments affect healthy tissues as well as cancerous ones, there may be side effects from treatment with these therapies. Recovering from surgery or a bone marrow transplant also can be very challenging. Sometimes treatment side effects may become severe enough that your doctor will discontinue or reduce your level of treatment for a short period while your healthy tissues recover. Some side effects due to medication, such as drowsiness, may diminish as you become used to taking the medication.

Being proactive in managing your side effects will help you enjoy the best quality of life during treatment and beyond, and may help you lessen the need for breaks between treatment cycles for allowing healthy tissue to recover. This guide presents some techniques for coping with the most common side effects from treatment, but by no means is this a comprehensive listing of all side effects. Make sure you discuss all of the potential side effects of your particular therapies with your doctor so you know what signs and symptoms to look for, steps you can take to help yourself and particular events that should trigger a call to your doctor. **The most common side effects of radiation and chemotherapy and their management are discussed briefly in this section. To summarize, they are:**

- Fatigue
- Pain
- Nutritional Issues
- Nausea and Vomiting
- Hair Loss
- Constipation
- Diarrhea
- Skin Reactions (Radiation)
- Nerve and Muscle Reactions
- Mouth and Throat Problems
- Low White Blood Cell Count
- Low Platelet Count
- Drowsiness and Confusion
- Sexual Side Effects
- Urination Problems
- Sinus Problems

Each of these side effects and its management is discussed in this section of the guidebook.



## MANAGING CANCER-RELATED PAIN

Pain is whatever a person experiencing it describes it to be. The goal of pain management is to give you maximum pain relief with minimal side effects. The key to effective pain control is to treat the pain before it becomes severe. When your pain is controlled, you are better able to sleep and eat, are less fatigued and will have greater peace of mind.

### What Is Cancer-Related Pain?

Pain related to cancer may come from a tumor pressing on bones, nerves or body organs. It also can be caused by the treatments for cancer. Your cancer-related pain may be controlled with a 24-hour/day schedule of medicine. You may occasionally have “breakthrough pain” (when your pain is not in control). Your doctor may prescribe a different, single-dose medication to take if breakthrough pain occurs.

### Describing Your Pain

It is important to describe your pain carefully to your doctor, so that appropriate medicines may be prescribed for you. It may be useful to track your pain with a personal log or journal so you can easily provide helpful

information. Some words you might use to describe the pain are “aching,” “tingling,” “sharp” or “throbbing.” Be sure to describe the duration of your pain. Does it come and go, or is it constant? What makes your pain better or worse? Where exactly does it hurt? These descriptions and answers to these questions will help your doctor understand clearly when you are starting to feel pain relief.

### Ways to Control Pain

There are a number of ways to reduce and control pain. They may involve a combination of medication and non-medication approaches. Those without medication include:

- Skin and muscle stimulation: Massage, acupuncture, hot/cold packs and vibration
- Imagery exercises: Calling to mind pleasant and relaxing images to soothe yourself
- Relaxation exercises: Meditation, yoga and focused contraction/release of muscles
- Distractions: Reading, music, humor and talking to friends

### Types of Pain Medicine

Many medicines are used to treat pain. You may be given one or more medications, depending on the type,

location and severity of your pain. Always check with your doctor before taking any new pain relievers or changing dosages of currently prescribed medications.

Do not worry that you will become addicted to pain medicine. You are taking the pain medication for a reason – you have pain! Cancer patients do not usually develop addiction to pain medications and should be able to stop taking this medication when their pain diminishes.

**The following types of medications are used to relieve pain, either alone or in combination for better effect.**

**Most of them will need a doctor's prescription:**

- Mild to moderate pain: Over-the-counter drugs such as acetaminophen (Tylenol), naproxen sodium (Aleve) and ibuprofen (Advil)
- Moderate to severe pain: Opioids such as morphine, hydromorphone hydrochloride (Dilaudid), oxycodone hydrochloride (Oxycontin), fentanyl patches (Duragesic), and oxymorphone hydrochloride (Numorphan)
- Tingling or burning pain: Antidepressants such as amitriptyline and imipramine, and anticonvulsants like Tegretol and Dilantin
- Pain from swelling: Steroids such as prednisone and Decadron

## Delivery of Pain Medication

**You may receive pain medication in the following ways:**

- Orally: By mouth.
- By Patch: Medication is embedded in a patch and applied to your skin; it is changed every two to three days.
- By Injection: Medicine is delivered through a needle into your skin, your muscle or sometimes directly into your spine (an epidural).
- Intravenously: A needle is placed into your vein and remains there. This may be connected to "Patient-controlled Analgesia" or PCA, which allows you to give yourself pain medication as needed in pre-selected doses as prescribed by your doctor.

## Side Effects

There may be side effects from pain medicine. Notify your doctor about any side effects you experience to see whether changing your dosage or medication will make you more comfortable. This guidebook offers suggestions for managing some of them. Common side effects from pain medication include: constipation, nausea, drowsiness, slowed breathing, itching, confusion and dry mouth.

## MANAGING CANCER-RELATED FATIGUE

Fatigue is one of the most common side effects of treatment in cancer patients. This fatigue can be physical, mental or even spiritual. It may range from mild to severe, where just getting out of bed feels challenging. Everyday activities, such as household chores or walking a short distance, can feel overwhelming. This is more than the tiredness one feels because of a poor night's sleep. It is important to try to relieve fatigue because you want to have enough energy to complete your treatments and enjoy a good quality of life during treatment.

## Reasons for Fatigue

The majority of cancer patients will feel tired at some points during their treatment cycle. Medications you are taking, lack of sleep, poor nutrition, weight loss, hormonal imbalances and energy used by your body to repair itself after radiation, chemotherapy or surgery, may all be fatiguing. Emotions such as anxiety and depression also can make you feel tired.

Chemotherapy treatments may destroy the red blood cells you currently have as well as affect your ability to produce new red blood cells. A very low red blood cell count (known as anemia) limits the body's ability to distribute energizing oxygen. Anemic patients also can feel short of breath, which slows them down. Radiation therapy treatments may cause fatigue as your body consumes extra energy healing any healthy tissues affected by the radiation.



**Signs of Fatigue**

- Mental or physical exhaustion or weariness
- Feeling like you have no energy for regular activities
- A feeling of heaviness in your arms and/or legs, making them difficult to move
- Lack of desire to do everyday activities
- Difficulty concentrating or thinking clearly
- Less attention spent on personal appearance

**Anemia-related fatigue**

Your blood may be tested periodically during treatment to monitor for anemia, which is the state of having a very low red blood cell count. Anemia can cause fatigue because your body does not have the red blood cells it needs to carry oxygen to your body's tissues. If your red blood cell count dips too low, the doctor may prescribe blood transfusions and/or medications to help your bone marrow recover its red blood cell production capacity.

**Rest and Energy Conservation**

While rest and sleep are important, you need to be careful not to overdo it. Too much rest can actually make you feel more tired. Your doctor may prescribe a sleeping aid if you cannot sleep well. Rest before you get tired and know that some days may be better than others.

**Activity and Exercise**

You should try to stay active as much as you can. Regular but gentle exercise, such as walking, yoga or Tai Chi, may help you feel more energized. Alternate periods of rest and activity.

**Nutrition**

Drink plenty of fluids (8-10 cups a day) and eat nutritious, high-protein, high-fat foods. Be sure to get enough calories to maintain your energy. Ask a nutritionist about the nutrients you need. If you are anemic, you may find eating iron-rich foods or taking iron supplements may help. Work with your healthcare team to manage any stomach or bowel distress that can interfere with nutrition. If you are having trouble preparing meals, ask about community meal programs.

**Task Management**

Spread your activities across the day and across the week, so you can have rest breaks in your schedule. Ask for help with housework and errands. If you need assistance, your hospital's social worker may be able to help you find community resources to assist you with everyday activities.

**Be Good to Yourself**

Have some fun! Do things that will help to restore your spirit and energy. Bird watching, visiting with a good friend and listening to music are all great activities. Try to do these pleasant things at least three times each week. If these do not help, talk to your doctor about medication that may improve your mood.

**COMMON QUESTIONS****How Much Should I Rest if I Am Fatigued?**

While you may want to increase your sleep time and take occasional naps, too much rest can actually make you feel more tired. Try to keep up your activity level each day, but do not push yourself too hard. Resting too much during the day may make it hard to sleep at night.

**How Do I Know if I Am Making Progress Fighting My Fatigue?**

We recommend you keep a journal and chart your response to activities. This will help you recognize your limits and see your progress. It also will help you discuss your progress with your doctor.

**How Can My Family and Friends Help?**

Ask for their assistance with things that tire you. Let them know this is not ordinary tiredness you feel. You may need to defer some activities until you feel stronger.

**What Emotional Support is Helpful?**

Some patients find it helpful to join a support group where they can share their feelings and concerns with other patients. Many national organizations sponsor support groups in local communities, as well as online support groups on the Internet (refer to the Support

Services section of this guidebook). Writing down your feelings in a journal also may be helpful, as well as meditation and being with good friends and family.

**Remember, to manage your fatigue...**

- Alternate rest and activity
- Eat well
- Ask for help from family and friends
- Plan ahead so you are efficient, save time and labor as much as possible
- Discuss your fatigue and its management with your healthcare team

## NAUSEA AND VOMITING

Nausea and vomiting may be caused by a number of things associated with cancer. Certain chemotherapy regimens may cause nausea. Radiation therapy to the abdomen may cause nausea. Pain medication, when first started, also may cause nausea.

There are a number of ways to help avoid or minimize nausea and vomiting. For chemotherapy-associated nausea and vomiting, doctors have many excellent medications today, called antiemetics, which help the majority of patients avoid severe nausea and vomiting. These medications may be given before, during or after treatment for the first few days. Doctors know which chemotherapy regimens often cause nausea and vomiting and need proactive intervention. Make sure you tell your healthcare team if you experience nausea, especially noting its timing, which may be before, during or a few days after treatment. Besides antiemetics, your doctor may be able to alter the dosage or timing of your therapy to help you, as well.

For pain medication-related nausea, altering your pain medication dosage level or frequency may bring relief, so be sure to share any association of nausea caused by pain medication with your doctor.

Radiation-related nausea will usually pass after treatment finishes and your healthy tissues have time to fully recover.



Nausea and vomiting may prevent you from eating enough and can eventually result in weight loss.

**Your physician may prescribe medications and suggest other methods to lessen these side effects, such as:**

- Snack on toast, crackers or pretzels
- Eat soft and bland foods like yogurt, sherbet, angel food cake, oatmeal, skinned chicken, and bland fruits and vegetables
- Try icy liquids such as Popsicles® and ice chips
- Avoid fried, greasy and fatty foods
- Eat small amounts slowly, and rest after meals
- Avoid spicy, hot foods and stay away from foods with strong odors
- Do not eat your favorite foods at times you feel nauseous – this will help you later avoid associating them with nausea
- Let someone else do the cooking
- Eat cool foods to minimize odors from cooking

Always check with your healthcare team to make sure the foods and supplements you eat are appropriate for your care, and ask if there are medications that may help you.

## MANAGING NUTRITION FOR CANCER PATIENTS

Overall nutrition is important for good health, but especially for people being treated for cancer. Good nutrition during your cancer treatment helps support you during treatment and helps you complete treatments on time. It helps you feel better, stay stronger and may help you recover more quickly. Nutrition also is important for a healthy immune system, your body's defense system against cancer and infections.

Poor nutrition can result in weight loss and muscle loss, which can contribute to fatigue and weakness. Your nutritional needs for calories and protein increase during treatment. Protein is needed to build, repair and maintain tissue as well as to help fight infection. Good sources of protein include meats, eggs, peanut butter and dairy products. Calories are needed to maintain your weight and sustain your body's basic energy needs. Adding

snacks between meals can help increase calories.

We have provided some helpful suggestions for getting good nutrition below. Some side effects, such as a lowered white blood cell count or nausea and vomiting, can alter your nutritional needs. Your doctor may suggest that you work with a registered dietitian nutritionist who is trained in helping cancer patients get enough nutrition. A registered dietitian nutritionist can help you understand which foods and fluids, and in what amounts, are right for you.

### Eating Right

Maintaining your weight is a good indicator you are getting enough calories. When you lose weight, you are not meeting your body's need for calories. You may think you are losing only fat tissue, but in fact you are most likely losing muscle mass. When you lose muscle, you feel weak and fatigued. Your immune system may become weaker as a result of weight loss. Weight loss is not desired during your cancer treatment. Try to maintain your weight and make sure you eat enough protein. For more information, ask to see a registered dietitian nutritionist.

## TREATMENT EFFECTS ON NUTRITION

### Loss of appetite

Adequate nutrition is sometimes difficult when you are experiencing some of the side effects of cancer treatment. Loss of appetite is one common side effect. Try eating five to six small, high-calorie/high-protein meals a day. Your nutritionist may recommend a commercial nutrition drink to supplement your diet. If the loss of appetite is severe, there are medications called appetite stimulants that your doctor may prescribe.

### Feeling Full

You also may have a feeling of fullness. Once again, eat five to six small, high-calorie/high-protein meals a day. Do not fill up on low-calorie foods like broth, lettuce and diet soda. Water is good for you, but it has no calories or



protein and may cause a feeling of fullness. Choose fluids with calories (Gatorade, juice, milk and shakes). Drink between meals rather than with your meals to leave room for food.

### **Sore Throat and Mouth**

Sore throat and sore or dry mouth are some other common side effects. Eat foods that are cool or at room temperature. Try soft foods and drinks like milkshakes, yogurt, cottage cheese, custards and puddings. Also, eggs and tuna fish are great soft sources of protein. You may need to blend some of your foods to a baby food consistency if you experience trouble swallowing. Keep your foods moist with sauces, gravies and butter. Keep your mouth wet with frequent fluids or try ice chips. Ask your healthcare provider about medications and salves available to help relieve these side effects.

### **Changes in Taste/Smell**

You may experience changes in taste and smell, especially if you are being treated in the head and neck area or are receiving certain chemotherapy drugs. Some people say

that foods have a bitter or metallic taste. **Try some of these tips for making food taste better:**

- Eat foods that look and smell good to you
- Use plastic eating utensils rather than silverware
- Serve food at room temperature, and try tart foods such as oranges or lemonade
- Try using seasonings to help flavor foods (basil, oregano and rosemary are just a few ideas)

### **Vitamins and Minerals**

If you are eating a well-balanced diet, you probably are meeting all of your nutrient needs. If you are not eating well, consult your doctor about taking a multivitamin. High doses of vitamins and minerals can interfere with the effectiveness of treatment, so ask your doctor before taking any vitamin, mineral or herbal supplements.

## **HAIR LOSS (ALOPECIA)**

Hair loss varies, depending on the type of treatment you receive. Your doctor can tell you whether your particular treatment is likely to lead to hair loss.

For chemotherapy patients taking certain treatment medications, there may be hair loss. When it does occur, the hair may become thinner or fall out entirely. Hair loss can occur on all parts of the body. It may fall out gradually or in clumps. Your hair should grow back after the chemotherapy treatments are completed. To care for your scalp and hair during chemotherapy: use mild shampoos, soft brushes and low heat when drying your hair. Do not use brush rollers to set your hair, and do not dye your hair or get a permanent. You may wish to cut longer hair shorter, in anticipation of hair loss. Some patients choose to go ahead and shave off the remaining hair when hair loss is significant, to avoid coping with the loss process over the following days or weeks.

For radiation therapy patients, hair loss may occur within the area that is being treated. You should not lose hair on your head from radiation treatments unless your head is receiving the therapy. In this case, hair may be lost in its entirety or in patches. This is usually temporary but in rare cases, radiation-induced hair loss may be permanent.

If you lose hair on your head (permanently or temporarily), be sure to use a sunscreen lotion, wig, hat or scarf to protect your scalp and neck from the sun. For those interested in wigs, some insurance companies may cover the cost when prescribed by your doctor. Some local American Cancer Society (ACS) chapters have wigs available in their offices. The ACS also has a catalog that offers a variety of head coverings and wigs you can order by phone or mail. You may wish to obtain the wig(s) ahead of time so they are available at the point you need them. Make sure you save some hair, so you can match the wig to your natural color (if you are not taking the opportunity to make a change in color).

## CONSTIPATION

Certain pain medications may cause constipation. Some chemotherapy regimens may be constipating. This side effect also may occur if you have decreased your overall activity level. Find out from your healthcare team if you should anticipate this side effect because there are steps you can take to minimize or avoid constipation. If you

have not moved your bowels for two days, be sure to talk to your doctor about steps you can take to relieve your bowels. **Some key suggestions to fight constipation include:**

- Drink plenty of fluids (at least 8-10 cups of water a day). Sometimes warm or hot fluids may be more helpful.
- Your doctor may suggest you take a stool softener or bulking agent (to prevent constipation).
- If you become constipated, your doctor may recommend a laxative to relieve your discomfort.
- If your doctor says it is OK, eat high-fiber foods. Fruits (especially dried ones like raisins and prunes), green leafy vegetables and whole grain cereals are good fiber sources. Nuts and popcorn also are good sources.
- Exercise, if your doctor says it is all right. Just taking a short walk may be helpful.

## DIARRHEA

Certain medications and chemotherapy regimens may irritate your intestines, causing diarrhea. Radiation therapy to the abdominal area also may cause this side effect. Diarrhea can significantly dehydrate a person, so it is important to call your doctor if the diarrhea continues for more than a day so it can be treated. If diarrhea continues for many days, your doctor may wish to admit you to the hospital to ensure you are getting adequate nutrition and help you recover. **Some tips for coping with diarrhea at home include:**

- Avoid high-fiber foods. These foods include many fruits (especially dried fruits like raisins and prunes), green leafy vegetables and whole grain breads and cereals, as well as seeds, nuts and popcorn.
- Avoid caffeine and milk products.
- After checking with your doctor, try to consume more potassium-rich foods like bananas, potatoes and oranges to replace potassium lost from being ill.
- Ask your doctor about over-the-counter or prescription medications that can help.



## SKIN REACTIONS

Skin changes are sometime noticed during radiation therapy. These may include redness, increased pigmentation (tanning) or peeling. These reactions are expected and usually occur about two to three weeks after your initial treatment. They are usually temporary and should heal in time. Avoid direct sunlight to the area being treated. Should it become necessary, a special skin ointment may be prescribed for you as a treatment for the reaction. You may apply cornstarch as often as necessary to keep the area dry. Do not apply your own ointments, salves, deodorants, colognes, cosmetics, heat or any self-remedies on the areas being treated during your radiation therapy. Check with your nurse or physician about the use of over-the-counter skin products because many contain alcohol or fragrances that may irritate your skin. This caution includes the three-week period after your treatments are complete.

## NERVE AND MUSCLE REACTIONS

Some chemotherapy regimens may cause nerve or muscle reactions because the nervous system cells are affected. Some drugs cause peripheral neuropathy, which has the effect of making your muscles feel weak, tired or sore. **It also may cause the following symptoms:**

- Tingling, burning sensation in the hands or feet
- Weakness or numbness in the hands or feet
- Coordination and walking problems
- Difficulty with buttoning clothing or picking up small objects
- Jaw pain
- Stomach pain

It is important to report these symptoms to your healthcare team because they may become more severe over time if left untreated. There are not many treatments for this side effect at this time. Ask your doctor about nutritional supplements or medications that may be helpful. Your doctor may choose to slow your treatments down to minimize this side effect. These side effects usually go away over time as treatment is ceased but may sometimes linger as a long-term side effect for some patients.

## MOUTH AND THROAT PROBLEMS

The tissues of your mouth and throat may be affected by treatment. These changes may be temporary or can be permanent with certain types of radiation therapy delivered to the head and neck area. Some treatments may dry out your mouth (xerostomia). This may make these areas easily subject to damage from accidents, like chewing the inside of your cheek. Sores may develop in this area, which may make it harder to eat and drink. It is important to be proactive in treating developing sores and dry mouth and throat to minimize your pain. In addition, keep up your nutrition and fluid intake levels.

**Here are some tips for minimizing oral problems:**

- Brush your teeth regularly with a soft-bristled toothbrush to avoid irritating dry gums.
- A water jet tool or oral rinse may be helpful for inflamed gums. Avoid rinses with alcohol or salt. Your doctor may prescribe a rinse with a mild anesthetic (pain relief) agent in it.
- Have dental cleaning done before treatment.
- If you have dentures, remove and brush them thoroughly after meals. If your dentures are loose, ask your doctor when to have them adjusted because your gums may be inflamed during the treatment process.
- Some patients find it effective to take icy liquids such as flavored ices and ice chips during the chemotherapy treatment itself as a preventive measure. These icy items also may be soothing if you develop sores.
- Hard candy may help you produce saliva to ease a dry mouth.
- Lip balms can ease dry lips.
- Your doctor may prescribe artificial saliva substitutes if your dry mouth is severe. Be sure to maintain good oral hygiene because the lack of saliva can negatively affect your dental health.
- If oral pain is severe, your doctor may prescribe a topical pain solution for you to swish in your mouth and gargle with to make you more comfortable.
- Eat smooth, soft, mild foods to avoid irritation. Add moisture to your foods with extra butter and gravies.

If you have radiation therapy in the area of your throat, it may cause your salivary glands to function less effectively. Saliva is very important to your dental and oral health. In this case, you will need to ask your doctor about the best long-term care. The solutions listed above may help your oral health. However, if your salivary glands are affected as a long-term effect, make your dentist aware of this issue.

### Difficulty Swallowing

If your head or neck is in the radiation treatment field, or your throat is especially dry or has sores from chemotherapy treatment, you may experience pain when you swallow. To decrease this pain, your doctor may recommend a topical anesthetic, pain medication, artificial saliva and/or drinking sufficient fluids to keep the throat moist. It is important to maintain good nutrition during this time. Be careful with thin liquids, such as water or juice because they may be difficult to control while swallowing.

## LOW WHITE BLOOD CELL COUNT (NEUTROPENIA)

Chemotherapy regimens can sometimes kill your infection-fighting white blood cells along with cancer cells. If your white blood cell count falls very low, it is called neutropenia. As your white blood cell count drops, you are more likely to get infections. Your doctor may be able to prescribe medication to help build your white blood cell count, or to help you fight off an infection if you develop one. In some cases, your doctor may slow or delay treatment while your white blood cell count recovers. **If you develop a low white blood cell count, please take the following precautions until it has returned to normal:**

- Wash your hands often. Not washing your hands is a very common way that colds infect you. Wash your hands before meals, after touching items in public areas (shopping carts or railings) and after using the toilet.
- Avoid crowds where possible.

- Stay away from people you know have a cold or flu or from children who have been recently immunized.
- Try to get adequate rest.
- Avoid situations where you may be burned or nicked, such as barbecuing, shaving with a regular razor (use an electric razor instead) and gardening among the rose bushes.
- Use moisturizer to prevent dry skin cracking.
- Let your doctor know if you have a fever of 101 degrees F or more.
- After bowel movements, clean yourself gently. If you develop irritation or hemorrhoids, ask your doctor about treatment.

## LOW PLATELET COUNT

Just as chemotherapy can destroy white blood cells along with cancer cells, it also may destroy platelets in your blood, also known as thrombocytes. When this damage occurs, it is called thrombocytopenia. Platelets are produced in your bone marrow to do the job of helping your blood clot at points where you are “leaking,” such as a cut. If your platelets drop too low, you may have trouble clotting. Symptoms of this would be unusual bleeding, or if you seem to be bruising more easily. If you have these symptoms, notify your doctor. Treatment may include drugs to help you increase your platelets, or platelet transfusions.

## DROWSINESS AND CONFUSION

Some pain medications or chemotherapy regimens may cause drowsiness or confusion. You may need to work with your doctor to find the right level or type of pain medication that controls your pain but does not severely sedate or confuse you. If you are confused or drowsy, ask a loved one to assist you with staying organized and focused, especially so that you do not miss taking your medications or meeting appointments. If you are concerned about these symptoms, ask your doctor if a change in your medications may be appropriate or if you may expect the effect to go away as you go forward with treatment.

## LYMPHEDEMA

Lymphedema is a side effect that may develop when cancer treatment, or an infection related to treatment, damages or removes lymphatic vessels or lymph nodes that are part of your lymphatic system. When this damage becomes so great that the lymph fluid can no longer flow effectively, the affected area can swell. For example, after removing numerous lymph nodes in the armpit to check for the spread of cancer from the breast, the armpit or arm might swell. Lymphedema can develop immediately after an operation, or weeks, months and even years later after treatment. Ask your doctor whether your particular treatment program will put you at risk for this side effect, and make sure you understand precautions you should take if you are at risk.

### Lymphedema Symptoms

The buildup of lymphatic fluid and subsequent swelling reduces oxygen flow in the area. If left untreated, this swelling can slow wound healing and create an area of the body susceptible to infection (lymphangitis). Over time, affected tissue may become hardened without treatment. The swelling may or may not cause pain. In breast cancer patients, lymphedema may appear in the arm next to the area where lymph nodes were removed or radiation treatment was delivered. For patients who have had many lymph nodes removed from the pelvic area, swelling may appear in the legs, ankles or feet. **Signs or symptoms of lymphedema to watch for include:**

- Swelling in the area near where lymph nodes were removed
- A full sensation in the limb(s)
- Skin feeling tight or ready to burst
- Decreased flexibility in the affected area (hand, wrist or ankle)
- Difficulty fitting into clothing in one specific area
- Ring/wristwatch/bracelet tightness
- Pitting of the skin – when you press the skin, it does not bounce back
- A sensation of heat or pins/needles in the area
- Aching in a limb or in back of the shoulder
- Inability to pinch a fold of skin on one of your fingers between your finger and thumb

If you notice persistent swelling, it is very important that you seek immediate medical advice because early diagnosis and treatment improves both the prognosis and the condition.

### Preventive Measures

If your doctor feels you are at risk for lymphedema, you may be asked to take preventive measures to minimize the chance of developing it. **Discuss the following measures with your doctor to see if you should take any of these precautions:**

- Never allow an injection or a blood drawing in the affected arm or leg.
- Never have blood pressure checked in the affected arm or leg.
- Keep the affected area spotlessly clean. Use lotion (aloe vera) after bathing. When drying, be gentle but thorough. Make sure it is dry in any creases and between fingers and toes. Aloe vera deodorant also is recommended.
- Avoid vigorous, repetitive movement such as scrubbing, pushing or pulling on the affected tissue.
- Avoid heavy lifting with the affected arm. Never carry heavy handbags, shoulder-strap bags or luggage. Do not lift more than five pounds with your arms or 15 pounds with your legs.
- Do not wear tight jewelry, elastic bands, socks, stockings or undergarments on the affected limb.
- Avoid extreme temperature changes when bathing or washing dishes. Avoid saunas or hot tubs. Keep the area protected from the sun.
- Avoid bruising, cuts, sunburn or other burns, sports injuries, insect bites and cat bites.
- Wear gloves while doing housework, gardening or any type of rough work.
- When manicuring your nails, avoid cutting your cuticles. Do not wear sandals or open-toed shoes. Always wear shoes both indoors and outdoors.
- Exercise is important, but consult with your therapist. Do not overtire the affected area. If it starts to ache, lie down and elevate the affected limb. Recommended exercises: walking, swimming, light aerobics, bike riding and specially designed ballet or yoga.

- When traveling by air, patients with lymphedema (or who are at risk) must wear a compression bandage. Additional bandages may be required on a long flight.
- Use an electric razor for shaving. Maintain the electric razor properly, replacing heads as needed.
- Warning: If you notice a rash, blistering, redness or increase in temperature of fever, see your physician immediately.
- Maintain your ideal body weight by eating a diet that is rich in vegetables, fruits, whole grains, herbs and spices. Ensure your diet is low in fat, meats, sodium, sweets, seeds, and includes minimal dairy and processed food products. Avoid smoking and alcoholic or caffeinated beverages.

### Treatment

Treatment of lymphedema depends on the severity. For example, treatment of severe lymphedema consists of one to two hours of daily treatment for about a month. A lymphatic-trained therapist performs a specific form of light massage (known as manual lymphatic drainage) and wraps the area with compression bandages. The patient also receives physical therapy. Education on skin and nail care also is included. Phelps Health has therapists on staff who are trained in the area of lymphedema.

Treatment for lymphedema will depend on its cause; whether it is lymphatic damage because of treatment or infection, or existing medical conditions you may have, such as fragile skin, or heart and vascular problems. Consult with your doctor before using any of the treatments mentioned below. Treatment may include:

- Elevation of the affected limb
- Compression garments or sleeves
- Special bandaging to apply compression
- Manual lymphatic drainage — a special method of massage that moves the accumulating lymph fluid from the unhealthy area of the body to the healthy area
- Special skin care and diet
- Visualization exercises and emotional support

Patients can find dealing with lymphedema to be very challenging physically and emotionally. Report any symptoms of lymphedema to your healthcare team immediately, and ask about treatment and support resources to help you with this side effect.

## SEXUAL ISSUES

Cancer treatment can have a variety of effects on people's sexual lives. It can affect how interested you are in sex, for a variety of reasons. Some treatments may cause temporary, or possibly permanent, impotence in men, or discomfort with intercourse for women. If changes are permanent, a couple may need to redefine how they express their love for each other. We discuss some of the issues here and offer some suggestions for managing them. Sometimes a couple may find a counselor or sex therapist helpful for working through these issues together. Then you may have the pleasure of learning how to be comfortably intimate with your loved one under these new circumstances.

### Low Libido (Lack of Interest in Sex)

**There are a variety of reasons your interest in sex may be affected by cancer treatment. They include:**

- Lowered self-image, perhaps because of scarring or loss of a body part from surgery, or addition of something like an artificial opening for breathing or for passing urine and stools
- Depression and stress
- Hormonal therapy
- Sexual identity issues, if fertility is lost
- Just not feeling well

Your sexual partner needs to understand all the emotions and physical changes you are feeling that stop you from wanting intimate contact with him or her. It is important that you be open and talk about your feelings, worries and desires with your partner. Low interest in sex, as well as other pleasures in life, is common when dealing with a life-threatening illness. For instance, a woman may fear that the lack of a breast will make her unattractive to her husband. On the other side, the husband may not want to ask his wife for sex until she feels better after surgery. Without talking about their feelings, she may feel unwanted when really he is just trying to be thoughtful. He may feel rejected, when she just is worried she does not appeal to him. Communication is the key to working through these issues with each other.

### Erection Problems

Men may have problems or be unable to have an erection because of cancer treatment. This problem is known as erectile dysfunction (ED). **It may be caused by:**

- Prostate cancer surgery that damages the nerves that create a man's erection

- Damage to the blood vessels that feed an erection
- Hormone therapy that suppresses testosterone, which both supports the erection itself as well as the libido feeding the erection
- Surgical removal of the testicles, which also suppresses testosterone

Many men take 6 to 12 months after treatment to return to normal with their erections. Not all men recover their functionality. There are a number of ways to treat ED. They include drug therapy (oral or self-injection) that promotes blood flow to the penis, penile vacuum pumps to stimulate blood flow and penile implants of various types. Discuss your symptoms and concerns with your doctor to find the appropriate solution for you.

### Inability to Ejaculate

A man does not need an erection to have a climax. If your prostate is removed, however, your orgasms will be “dry” because the prostate no longer produces seminal fluid. Another kind of prostate cancer operation, transurethral resection, actually redirects your ejaculate back into your bladder, so your urine may appear cloudy. This is called retrograde ejaculation. Make sure you understand how prostate cancer surgery is expected to affect your erections and ejaculations.

### Painful Intercourse for Women

Radiation therapy to the vaginal area may narrow it down. Ask your doctor if you should avoid sexual intercourse while receiving radiation therapy to the vaginal area. After treatment, your doctor may prescribe a device to help you gently stretch the vaginal tissues to make intercourse comfortable again. Some surgeries in the pelvic and vaginal areas also may cause intercourse to be painful.

### Vaginal Dryness

Some medications, chemotherapy regimens or even surgeries, can cause a woman’s natural lubrication in her vagina to dry up and cause intercourse to be painful. There are a number of lubricants on the market that can make intercourse more comfortable. Do not use

petroleum jelly, which may promote vaginal infections. Use only water-soluble products.

### Heightened Sexual Desire

Both men and women may have courses of therapy (estrogen for women, androgen for men) that may increase sexual desire.

## URINATION PROBLEMS

Pain when urinating may occur if you are receiving radiation treatment to the abdomen and pelvis. If this occurs, let your doctor know, and be sure to drink plenty of fluids and avoid alcohol, caffeine, citrus and carbonated beverages.

## SINUS PROBLEMS

Treatment with certain chemotherapy drugs can irritate the lining of your nose and sinuses (passages that lead the air from your nose to your throat). Radiation therapy to the nasal area can dry the nasal tissues out. If you experience nasal irritation or sinus problems, alert your doctor, who may be able to prescribe medications or nasal rinses to make you feel better.



# COMPLEMENTARY THERAPIES

Complementary therapies are techniques you can try that may enhance or complement the effectiveness of traditional treatments like surgery, chemotherapy and radiation therapy, or help combat their side effects. This section gives an overview of some of these therapies.

Before starting any complementary therapy, be sure to review your plans with your doctor to ensure it will work well with the traditional treatment being provided to you. It is especially important to check with your doctor about over-the-counter herbs and dietary supplements, which may interfere with the therapeutic effectiveness of traditional treatments.

As you consider therapies outside standard clinical practice, the following issues should alert you to closely check into the value and safety of treatment:

- Has this treatment been in clinical trials? This is especially important if the manufacturer is making claims about how well it works.
- Have reputable medical journals written about this treatment? These journals would include the Journal of the American Medical Association, the New England Journal of Medicine, Cancer (the journal of the American Cancer Society) and the Journal of Clinical Oncology.
- Claims of persecution by “the establishment.” Laetrile is an example of this suppression claim. The National Cancer Institute studied laetrile thoroughly and found no cure or improvement in any patients who took it.
- Claims of “no negative side effects” as a selling point for the therapy.
- A practitioner discourages you from discussing the treatment with your oncologist. Herbs, supplements and high-dose vitamins can cause your traditional chemotherapy or X-ray radiation treatment to be blocked or intensified, so it is essential you talk to your oncologist about all treatments you are considering.
- The treatment focuses only on diet. No research has substantiated that diet alone can stop cancer. Some macrobiotic diets may actually slow your blood count from returning to healthy levels.
- Claims the product is a “natural” therapy. Many natural items can be just as toxic as “man-made” ones. Saw palmetto, for instance, is something that prostate cancer patients have taken to help their urinary symptoms. However, researchers at the Cancer Institute of New Jersey found that saw palmetto contains estrogen, which can throw off the results of the prostate specific antigen test and actually made the tumor “androgen independent” and much harder (or impossible) to treat.

Suggestions for therapies that many other cancer patients have found helpful are listed in this section.

## RHYTHMIC BREATHING

This mind-body technique helps you find your relaxation response, an important muscular response that relaxes your muscles, which can help relieve pain. Rhythmic breathing requires a quiet place to lie down or sit comfortably. Resting your arms at your sides and keeping your legs slightly apart will promote good circulation. Close your eyes and then inhale slowly and deeply, feeling your chest rise and your abdomen expand. Exhale slowly and completely, and feel the tension leave your body as you breathe out. Continue to do this slow, steady breathing pattern for 5-10 minutes. As you finish, give yourself a calming and positive thought like “I feel relaxed and ready to face the day.”

## PROGRESSIVE MUSCLE RELAXATION

Start rhythmic breathing (see above). As you breathe in, tense the muscles in your body, starting with your feet and ankles. As you breathe out, relax those muscles and go limp. Move the tightening exercise from your feet and ankles up your body, little by little (calves, thighs, stomach, chest, arms and shoulders). This exercise may help you feel relaxed and alert.

## VISUALIZATION

This mind-body technique, also known as imagery or guided imagery, may help with both pain and nausea management. It also may help combat boredom and even sleeplessness. It combines rhythmic breathing with imagining mental pictures that have positive meaning for you. For a child, this might mean picturing marching teddy bears carrying away pain away from his or her



body. For another patient, it could mean seeing pain as a bright flame that he or she pictures pouring water on, dousing it into coolness. Part of the success with this technique is to clearly picture an image that has meaning to you to represent your pain or your nausea, and then imagining something pleasant in contrast to that pain or nausea image.

## DISTRACTION

Distraction pulls your brain away from thoughts about pain or nausea into other thoughts. Pleasant music, a good movie on TV or video, an interesting book or even a good conversation with a friend can all serve as distractions. Distraction may diminish or even let you forget about negative feelings or sensations you are experiencing for a while.

## HYPNOTHERAPY

Hypnosis helps you enter a very relaxed state where you are open to the power of suggestions that can make you feel better after you complete the hypnosis session. You

may begin hypnosis with a trained practitioner who may offer suggestions like, “You will not feel any pain when you awaken.” Self-hypnosis, where you put yourself under the hypnotic state, is much more difficult to achieve, and not everyone may find it useful for blocking pain or nausea. Scientists are not clear exactly why hypnosis works, but some patients find it an effective technique.

## BIOFEEDBACK

With biofeedback, special equipment is used to train people to take control over bodily processes we normally think of as involuntary, or not under our control. These processes include directing muscles to relax and the pulse to slow. Muscle tension can make pain worse, so being able to relax your muscles may help you manage pain. The equipment measures your bodily responses and provides visual and sound signals showing these responses. This “biofeedback” lets you know when your mind is effectively controlling your body and helps you understand what is necessary to relax physically. With time, some patients may find they have this self-control over their bodies without the equipment to provide biofeedback.

## MEDITATION

Meditation is a very old form of relaxation and stress relief that has been medically validated as a way to relieve pain, lift your spirits and help you find inner peace with the world around you. It includes elements of techniques discussed above and goes beyond them. Meditation does not require special clothing and does not involve drugs or other expensive tools or treatments. It does not have to be practiced as a part of any religion to be of benefit to you, although its ancient roots do begin in religious practice. Meditation simply requires your attention and focus to gain benefit from its practice.

When you have cancer, it may seem like you are not in control as your doctor tries different treatments and your body works to fight off the cancer. Meditation is a way for you to take control of how you feel and react to the world around you, which may result in you feeling less stress and more relaxed.

There are many different techniques for meditation. Most require you to sit quietly and allow internal thoughts and external sensations to exist without you reacting to them. While meditation will not “take away” your pain, it can help move that pain, both emotional and physical, out of your focus, so that it is less distressing to you.

While meditation is fairly simple to do, to gain full benefit from it, you must practice it regularly. It does take discipline to remain still in both your mind and your body. Daily practice, usually at least 20 minutes, will help you find full benefit. It is in the repetition of the meditation that the relaxation response shows up. Meditation may be practiced along with other mind-body techniques, such as guided imagery and relaxation exercises.

Not everyone benefits from meditation. Researchers are not sure why. If meditation does not work for you, be sure to explore other methods of creating the relaxation response in your body. These can include Tai Chi, praying with a rosary, doing yoga or even simply walking in a peaceful spot. Meditation and other mind-body techniques are not a substitute for conventional treatment but can be powerful complements to make

your body receptive to the healing power of those treatments.

## HOW TO MEDITATE

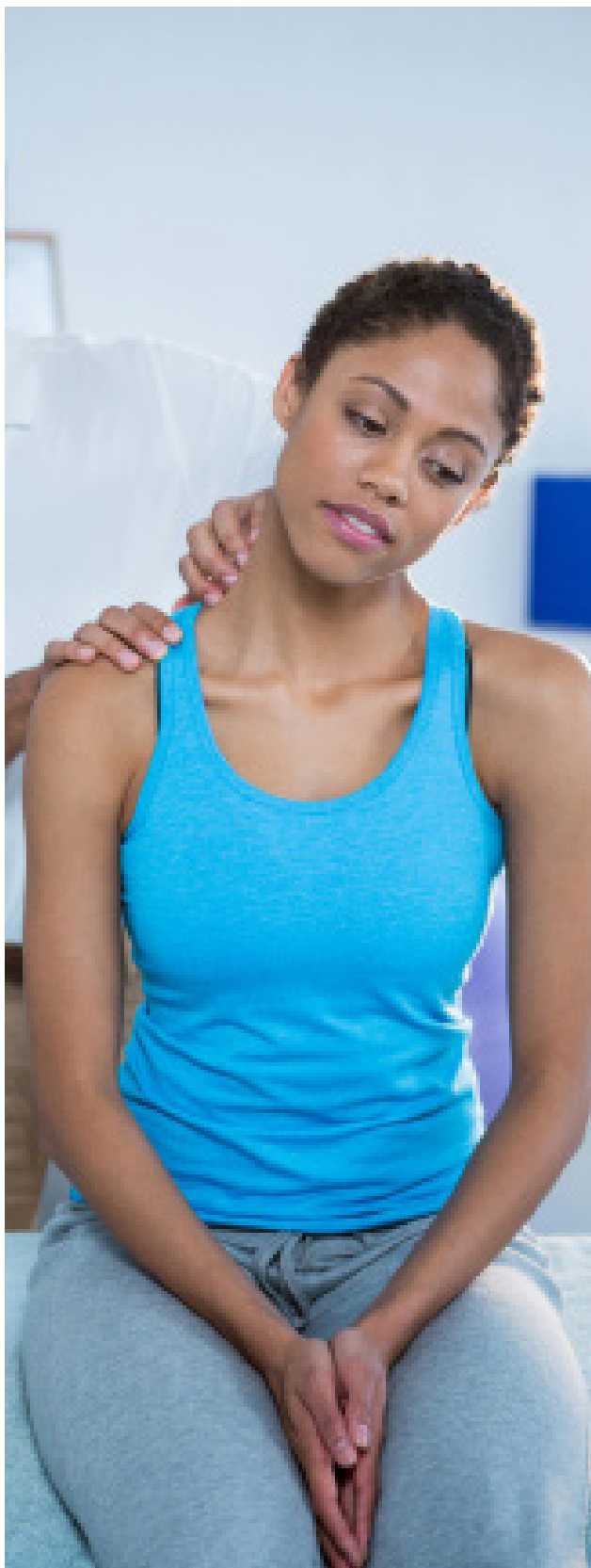
Choose a quiet place where you will not be disturbed for at least 10-20 minutes. Do whatever you need to prevent interruption – close the door, turn off the phone and let friends/family know not to bother you. To keep yourself from worrying about the time, set an alarm to let you know when to stop meditating.

Meditation needs to be done in a comfortable posture for you. If you do not have back or knee pain, use the classic position of sitting cross-legged on a pillow on the floor. The pillow makes sure your back and neck stay in a comfortable neutral position (not too much or too little sway in them). This classic position may be held for long periods of time.

Others may find the classic position uncomfortable because of arthritis, recovery from surgery or any number of other reasons. Try sitting on a chair with your back supported and your feet flat on the ground. Remain still if you can – but do not suffer! Move as needed to stay comfortable. If you cannot sit for long periods, try walking in a quiet area without obstacles. Walk slowly so you can concentrate on your meditation. You can meditate lying down if you need to, but you may fall asleep as you relax.

The next step is to quiet your body and mind. Take a few deep, relaxing breaths. Start to pay attention to your focal point – your breath, a phrase or something to look at steadily. Focus your attention gently, and if it wanders, just bring it back. Let your thoughts and feelings come to you, but do not spend time on them; let them pass by without judging them. After some time meditating, you may feel your body relaxing. When you finish meditating, take a few deep breaths and let your attention slowly come back to the present.

You may find that your body or mind becomes uncomfortable in some way during the meditation. Maybe you become bored. This distraction can happen when you first try meditation and is normal. Over time



(it may take a few weeks), most people can keep their focus better and become more deeply relaxed. It is this relaxation response that will lead you to all of the beneficial effects of meditation.

## HERBS AND DIETARY SUPPLEMENTS

The research on the effectiveness of various herbs and dietary supplements in treating cancer and their side effects is ongoing and controversial.

**The clinical effects are often difficult to predict due to the following:**

- Lack of human studies
- Lack of availability of the form and/or dose used in the studies
- Variation in potency of the supplement, which is determined by the part of the plant used, harvesting methods and processing methods
- The United States Food and Drug Administration does not evaluate safety or labeling of dietary supplements before they are sold

There is a tremendous amount of information about herbs and dietary supplements that are shared between patients as “success stories,” on the Internet as “proven solutions” and in marketing materials by the companies that profit from the sale of these supplements. Remember, your cancer may not be the same as another patient’s cancer or treatment, and therefore, the supplement may not be the best for you.

Herbs and dietary supplements are active compounds that require metabolism along the same pathways that chemotherapy and other prescription drugs require. As a result of this, herbs and dietary supplements could interact with — increase the side effects of or decrease the effectiveness of — other medications you are taking, including your cancer treatments.

Antioxidant supplementation is a controversial subject. Some studies suggest taking antioxidants may be beneficial; however, just as many studies say it may be harmful. It is possible that antioxidants protect

tumor cells, in addition to healthy cells, from the oxidative damage intentionally caused by conventional treatments, such as radiation therapy. This may reduce the effectiveness of treatments. There is no evidence to support that those antioxidant-rich, whole foods or drinks should be avoided during cancer therapy. It is believed that the level of any one particular antioxidant in a whole food is unlikely to interfere with treatment. The same cannot be said about high-dose antioxidant supplements.

Before using ANY supplements, it is important to consult your doctor to find out what the doctor knows about that supplement's use and whether that supplement will interfere in any way with the more traditional treatment planned for you.

## MASSAGE

The art of massage therapy has been around for many centuries. There are many different schools of massage that emphasize slightly different ways to rub and stretch your muscles to achieve a relaxing effect. Other relief that has been documented includes pain relief through release of endorphins, the body's own natural painkillers, and improved blood flow to vital organs. There is even some indication that your immune system function may be improved with massage. Another benefit of massage is that it provides the warmth of human touch at a time when you need extra emotional support as you fight your cancer. If the massage is done in association with something like chemotherapy (just before), it may help make chemotherapy sessions something to look forward to.

It is generally believed now that massage will not move cancer cells throughout the body; however, as with any complementary therapy, it is best to consult with your doctor before beginning massage treatments. Other common sense cautions include not massaging known areas of disease or strong inflammation. No matter which type of massage you enjoy, whether it is Swedish, shiatsu or others, let the experience be one that brings serenity and peace into your day.

## AROMATHERAPY

Religions have long used aromas as part of the experience of seeking higher awareness and observing your inner self. While the research is not conclusive about aromatherapy's benefits, its practitioners find that certain scents help promote different moods in people: alertness, calm, joy and tranquility. Use of pleasant aromas can be a very nice way to promote relaxation and peace for yourself. In major drugstores as well as specialty shops, you will see different aromatherapy offerings in the candle and perfume sections. Have fun smelling each one and seeing if a particular scent evokes a mood or feeling in you.

## YOGA

Yoga is the Sanskrit word for union. It focuses on uniting the body, mind and spirit together as you practice different postures. Your impression of yoga may be one of people achieving very difficult postures or positions, using great flexibility. The good news is that you can receive the benefits of yoga without becoming a contortionist. Some research indicates that yoga may create immune function enhancement, as well as improve sleep and digestion. Yoga has many gentle postures that allow people to achieve a calm and aware state. Many of the postures can be done in everyday places – your car, your office or sitting on the couch at home. Beginning yoga exercises focus on gentle stretching and quiet toning of the muscles. If you are interested, your hospital or local community recreation centers may offer classes in yoga that require little more than wearing comfortable, loose clothing.

## TAI CHI

Tai Chi Chuan is an ancient art that originated in China. Tai Chi, as it is practiced in the West today, can perhaps best be thought of as a moving form of yoga and meditation combined. It is a gentle enough exercise that even the very elderly practice it every day in China. There are a number of so-called graceful and slow-moving forms (sometimes also called "sets") that consist of a sequence of movements, many of which originated in the martial arts.



In Chinese philosophy and medicine, there exists the concept of chi, a vital force that animates the body. One of the main goals of Tai Chi is to foster the circulation of this chi within the body. The belief is that by doing so, the health and vitality of the person are enhanced. According to Chinese medicine, chi circulates in patterns that are closely related to the nervous and vascular systems. Tai Chi is closely connected with the practices of acupuncture and other oriental healing arts, which also use the chi concept. This concept of healthy energy and the meditative aspects of the form movements are what may be of interest to cancer patients.

## ACUPUNCTURE/ACUPRESSURE

The Chinese culture gave us the healing art of acupuncture, and its related cousin, acupressure. In acupuncture, tiny sterilized needles are placed at special points in the body to facilitate the flow of energy, also known as chi, through the body. This technique has been used in China for many centuries to treat a wide variety of ailments. The federal National Institute of Health has verified the usefulness of acupuncture for many patients for nausea and vomiting. Some cancer patients have found relief from pain and joint or muscle aches, as well. Acupuncture is a very skilled healing art; so ask your healthcare team for qualified referrals if you are interested in exploring this complementary therapy technique.

## JOURNALING

Writing in a journal is an easy-to-implement practice for tracking your reactions to treatment, as well as venting your feelings and organizing your thoughts. Regular journal writing promotes self-awareness and a clearer connection to what is in your heart and your mind. It may help you cope with the many changes that cancer and its treatment imposes on your life. Journaling can be a stress reducer. A journal “listens” without judging you or commenting on what you have to say. When you write in your journal, do not worry about spelling, punctuation or grammar; you are writing for yourself. Some people like writing in a simple school

notebook of lined paper, while others like to buy a special blank book in which to write. If a blank page intimidates you, ask yourself a question such as “How do I feel today?” or “What can I do to make myself feel better?” to give your writing some focus. Some people find daily writing is helpful. Others choose to write when they especially want to express their thoughts or feelings. In addition, reading what you have written before may help you come to a better understanding of your mind and heart.

## EXERCISE

Exercise brings all sorts of positive benefits to the body. These benefits include releasing endorphins, the natural painkillers of the body, strengthening muscle, relaxing the body and even serving as a distraction from feeling pain. Exercise can improve your breathing and blood circulation, which in turn promotes feeling less fatigue. We recommend you do not cease all activity levels. Inactivity weakens your body, at the time you need your strength most to fight your cancer.

Cancer patients may tend to overlook exercise as a source of energy and good feelings because they are often tired or in pain and “do not feel like it.” Obviously you must consider your body’s current state and listen to its signals. There may be times you feel very tired or sick and cannot exercise at all. If this is the case, be alert to the periods when you have more energy and take advantage of them with gentle exercises, such as walking, yoga or Tai Chi. There are even exercise programs you can do while sitting in a chair.

Although you should not begin any exercise program until you consult with your doctor, we strongly recommend you seek some regular exercise activity. Even a short, 20-minute walk each day will be of benefit. Ask your doctor for advice about starting an exercise program today.

## OTHER THERAPIES

There are significant schools of medicine outside the United States, including the Chinese school, Ayurvedic School and even Tibetan schools of medicine. These schools of medicine will often suggest use of complementary therapy methods as part of their treatment. If you seek help from practitioners of these other schools of medicine, be sure you fully review their suggestions for treatment with your traditional doctors before engaging in these different treatment methodologies. Additional therapies that may assist you in managing pain and nausea are listed in this guidebook's discussion of pain management and nutritional issues.



# SUPPORT SERVICES

Being proactive in your healthcare is always a good idea. This section offers additional resources, references and support services to help you navigate through your cancer journey.

## USING THE INTERNET FOR RESEARCH AND SUPPORT

The Delbert Day Cancer Institute (DDCI) patient portal empowers patients and their families to take an active role in treatment and gain a deeper understanding of their medical condition. The portal provides a secure access point for patients to view treatment summaries, test results, appointment schedules and educational resources. The portal also gives patients the opportunity to reduce wait times at hospitals by completing forms and questionnaires ahead of time.

The Internet has a tremendous amount of information about cancer and related topics. The Internet is like having a giant research library at your fingertips!

**However, there are some key things you should remember if you use the Internet to learn about your cancer and its treatment:**

- The members of your healthcare team are your first and best source for information. You should discuss your concerns and need for information with them. If you learn something from the Internet that you need help in understanding, please ask your healthcare professionals. Your healthcare team wants to make sure you have the information that is relevant to your care.
- The Internet can be a confusing and frustrating source of information for patients. Almost anyone can post anything to the Internet, without any formal check on the medical validity of what is being posted. Therefore, the quality of information on the Internet varies widely. For this reason, we recommend you begin research on the Internet at the major cancer organizations' websites, where the information has been carefully reviewed before being posted online. We provide the website addresses for these major organizations in this guidebook.
- Information about clinical trials is readily available on the Internet, both from government-funded and privately funded sources, like pharmaceutical companies. You may learn of a clinical trial that seems relevant to your cancer. You may bring that information to your doctors' attention so they can

discuss whether it is appropriate to consider for your particular case.

- The Internet is international, so you may find that treatment guidelines may differ for your cancer in other countries. This should not be a cause for concern. Feel free to ask your doctor about these differences.
- The amount of information you can find on the Internet can be overwhelming and even a bit intimidating. Starting with reputable, known sites, such as those listed in this guidebook, can help you be efficient in your research. Then, you are more likely to find the information you are looking for without spending too much time searching.
- As part of some of these websites, you can participate in listserver groups with other patients. If you have an email address, these groups allow you to correspond with others belonging to the same listserver. Listservers can be excellent places to share your concerns and get support from others who have already gone through or are now also going through the same experience. There are privacy issues to be respected and to consider when you register for these groups, as many (but not all) of them request you submit your name as well as your email address. Specific listserver groups exist for most of the major cancers, as well as some of the side effects that patients may experience, such as pain and fatigue. The Association of Cancer Online Resources provides access to over 99 lists at [www.listserv.acor.org](http://www.listserv.acor.org).

## EVALUATING HEALTHCARE ADVERTISING CLAIMS

How can you tell if an advertising claim for a "miracle" health-related product is likely to be phony, exaggerated or unproven? **The Federal Trade Commission (FTC) says these tip-offs generally signal a rip-off:**

- Phrases like "scientific breakthrough," "miraculous cure," "exclusive product," "secret formula" and "ancient ingredient"
- Use of "medicalese" — impressive words to disguise a lack of good science

- Case histories from “cured” consumers claiming amazing results, whose testimonials also imply that their experience is typical for everyone
- A laundry list of symptoms that the product is supposed to cure or treat
- A claim that the product is available from only one source, for a limited time
- Testimonials from “famous” medical experts without specifying names and their credentials, rather than from known, respected organizations that are verifiable
- A claim that the government, medical profession or research scientists have conspired to suppress the product

For further information about FTC warnings, to file a complaint or to get information about other topics, you may go online to <https://www.consumer.ftc.gov/health> or call toll-free (877) 382-4357 (FTC-HELP).

## PATIENT ORGANIZATIONS

### American Cancer Society (ACS)

Website: <http://www.cancer.org>

Phone: (800) 227-2345

Special Programs:

- Reach to Recovery connects breast cancer survivors with women undergoing breast cancer treatment

Counselors can provide referrals to community resources and medical information by phone or through the mail.

Extensive information is available on the ACS website.

Local offices may provide patient transportation and may stock wigs or prostheses to those in financial need. The

ACS also offers a catalog of special products for those with breast cancer or suffering hair loss. Some limited financial assistance is available for home healthcare, childcare, medical equipment and pain medication for those with little or no insurance. The ACS can intervene in medical insurance disputes, as well.

### CancerCare®

Website: <http://www.cancercare.org>

Phone: (800) 813-4673 (HOPE)

CancerCare® offers a wide variety of services to people with cancer and their loved ones, including support groups, one-to-one counseling, free teleconferences with experts, informational materials and referrals for homecare, childcare and financial guidance.

### Medscape

Website: <http://www.medscape.com>

This website offers an extensive collection of articles on the latest cancer research, practice guidelines, latest cancer news, conference summaries, information on cancer-related medications and related website links. To use this website, you must register and create an account. This website has in-depth “resource centers” on breast, prostate and lung cancers, as well as pain management and anemia-related fatigue. It also offers a weekly “MedPulse” email notification of the latest news on the specialties you choose.

### National Coalition for Cancer Survivorship (NCCS)

Website: <http://www.canceradvocacy.org>

Phone: (877) 622-7937

This patient-led organization has policies, publications and programs to empower cancer survivors.

### National Organization for Rare Disorders (NORD)

Website: <http://www.rarediseases.org>

Phone: (203) 744-0100

NORD is a federation of more than 140 not-for-profit voluntary health organizations serving people with rare disorders and disabilities. NORD offers a rare disease database, organizational database, used medical equipment and orphan drug designation database. A rare or “orphan” disease affects fewer than 200,000 people in the United States. NORD offers patient networking, newsletters, financial aid for medications and early access programs for investigational new drugs.

**Patient Advocate Foundation**

Website: <http://www.patientadvocate.org>

The Patient Advocate Foundation offers programs that provide free legal counseling in the areas of job and insurance discrimination, and intervention with creditors to renegotiate payments. This organization can direct you to federal and state aid sources. The Patient Advocate Foundation also connects patients to an oncology case manager that can answer questions about managed-care medical coverage and who can talk to your HMO to help resolve disputes about coverage.

## GOVERNMENT ORGANIZATIONS

**Cancer Information Service of the National Cancer Institute**

Website: <http://www.cancer.gov>

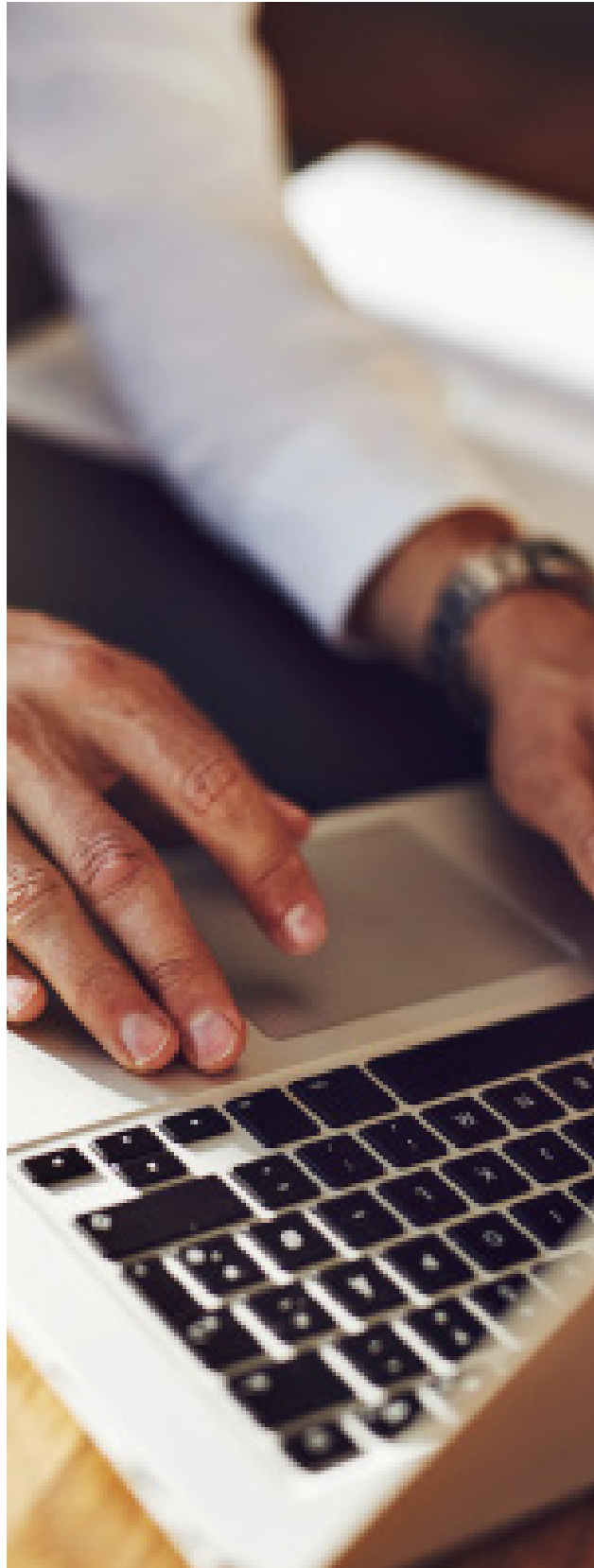
Phone: (800) 422-6237 (4-CANCER)

The Cancer Information Service provides information for patients through trained information specialists who can research the National Cancer Institute's extensive database of treatment options and send you selected summaries about these options. This organization also has information on clinical trials in your area and other information related to cancer. The majority of this information is on the Internet. The National Cancer Institute is the federal government's principal agency for cancer research and training. Through this website, you can find information about cancer topics, clinical trials, cancer statistics, research and funding as well as news related to cancer.

**healthfinder®**

Website: <http://www.healthfinder.gov>

This website includes medical dictionaries, an encyclopedia, journals, information about long-term care, nursing homes, health insurance, prescriptions, health fraud, Medicare, Medicaid, medical privacy and a listing of health information websites from government agencies, clearinghouses, nonprofits and universities.







#### Medicare

Website: <http://www.medicare.gov>

Phone: (800) 633-4227

Use this website or phone number for information on Medicare benefits and eligibility.

#### National Institutes of Health Clinical Trial Listing:

Website: <http://clinicaltrials.gov>

This website lists clinical trials that the National Institutes of Health are sponsoring. Not all clinical trials that run directly through drug or equipment companies or at medical centers will be listed here.

## NATIONAL ORGANIZATIONS FOR FINANCIAL, MEDICATION AND CO-PAY ASSISTANCE

#### CancerCare Co-Payment Assistance Foundation

Website: <https://www.cancercare.org/copayfoundation>

Phone: (866) 552-6729 (55-COPAY)

The CancerCare Co-Payment Assistance Foundation is a not-for-profit organization established in 2007 to address the needs of individuals who cannot afford their

insurance co-payments to cover the cost of medications for treating cancer. The foundation is proud to be affiliated with CancerCare, a national not-for-profit organization that has provided free professional support services including counseling, education, financial assistance and practical help to people with cancer and their loved ones since 1944.

#### Good Days

Website: <https://www.mygooddays.org/>

Phone: (972) 608-7141 or (877) 968-7233 (toll-free patient information)

This program provides assistance to underinsured patients who are diagnosed with chronic or life-altering diseases, including cancer, to help them access the medications they need.

#### HealthWell Foundation

Website: <https://www.healthwellfoundation.org/>

Phone: (800) 675-8416

This nonprofit organization provides financial assistance to eligible individuals to cover their co-insurance, co-payments, insurance premiums and deductibles for certain drugs and therapies.

**NeedyMeds**

Website: <http://www.needymeds.org/>

Phone: (800) 503-6897

NeedyMeds, a 501(c)(3) nonprofit organization, is an information resource on patient assistance programs that help patients who cannot afford their medications or other healthcare costs.

**Partnership for Prescription Assistance**

Website: <https://www.pparx.org/>

Phone: (888) 477-2669

This organization helps qualifying patients who have no coverage for prescription drugs to get the medications they need by connecting them to patient assistance programs. This organization offers access to more than 475 public and private programs, including 200 drug company programs that cover the cost of drugs for qualified patients.

**Patient Access Network Foundation**

Website: <https://www.panfoundation.org>

Phone: (866) 316-7263

This foundation provides financial support for out-of-pocket costs for a wide range of medications for chronic or life-threatening conditions, including cancer.

**Patient Advocate Foundation Co-Pay Relief Program**

Website: <https://www.copays.org/>

Phone: (866) 512-3861

This organization provides direct financial support to eligible patients, including Medicare Part D beneficiaries. This may include out-of-pocket costs for insurance co-payments, co-insurance and deductibles.

**Patient Services, Inc.**

Website: <https://www.patientservicesinc.org/>

Phone: (800) 366-7741

This nonprofit organization provides health insurance premium assistance, pharmacy co-payment assistance and co-payment waiver assistance for patients with chronic illnesses, including cancer.

**Rx Outreach**

Website: <http://rxoutreach.org/>

Phone: (888) 796-1234 (RXO-1234)

This nonprofit charity provides access to affordable medications. Rx Outreach offers more than 600 medications through its mail-order pharmacy to all 50 states, Puerto Rico and the Virgin Islands.

**RxAssist**

Websites: <http://rxassist.org/> or to link to your drug company's financial assistance program, visit <http://rxassist.org/contact>

This organization provides a comprehensive list and direct link to patient assistance programs for specific drugs from drug companies.

## PROFESSIONAL SOCIETIES

**American Society of Clinical Oncology (ASCO)**

Website: <http://www.asco.org>

Phone: (888) 282-2552 or (703) 299-0158

This society for oncology professionals offers a peer-reviewed journal, conferences, reports on the latest research and dedicated section of its website for people living with cancer, regarding clinical trials and patient guides.

**Oncology Nursing Society (ONS)**

Website: <http://www.ons.org>

Phone: (866) 257-4667 (toll-free)

ONS offers continuing education, research grants and conferences in oncology nursing. Through its allied organization, Oncology Nursing Certification Corporation, it offers the OCN® and AOCN® certifications for oncology nurses. ONS also offers extensive patient education information on its website and partners with organizations to create patient education materials.

**Bone Marrow and Organ Transplant****National Marrow Donor Program**

Website: <http://www.bethematch.org>

Phone: (800) 627-7692 (MARROW2)

This is a registry of volunteer bone marrow donors funded by the government. It matches donors and recipients, coordinates necessary tests and helps treatment arrangements. This program has an advocacy center to help with insurance companies and finding funding. References to support groups and educational publications are available.

#### **National Foundation for Transplants**

Website: <http://www.transplants.org>

Phone: (800) 489-3863

The National Foundation for Transplants offers direct financial aid and support in fundraising for bone marrow transplants, including account management services. This organization will work as a patient advocate in getting patients listed for transplant candidacy.

#### **Help Hope Live**

Website: <https://helphopelive.org/>

Phone: (800) 642-8399

Help Hope Live is a national 501(c)(3) nonprofit whose mission is to support community-based fundraising for people with unmet medical and related expenses due to cell and organ transplants or catastrophic injuries and illnesses.

#### **Miscellaneous Information**

##### **ADVANCE DIRECTIVES/HEALTHCARE SURROGATE FORMS**

Your local Office Depot or Staples stores often carry these forms. Forms also are available through Aging with Dignity by calling (850) 681-2010 or visiting the organization's website, <http://www.agingwithdignity.org>

##### **CLINICAL TRIALS**

CenterWatch Clinical Trials listing service

Website: <http://www.centerwatch.com>

Phone: (866) 219-3440

CenterWatch is a Boston-based publishing and information services company that provides information services about clinical trials. This company offers a notification and matching service, a drug directory and other patient resources.

#### **INCONTINENCE**

National Association for Continence

Website: <http://www.nafc.org>

Phone: (800) 252-3337 (BLADDER)

The National Association for Continence offers referrals to urologists who specialize in incontinence caused by cancer and its treatment, a resource guide directory of incontinence-related products and services, instructional videotapes and audiotapes for exercises to minimize leakage and a newsletter and other educational publications.

#### **LYMPHEDEMA**

National Lymphedema Network

Website: <http://www.lymphnet.org>

Phone: (800) 541-3259

The National Lymphedema Network can direct patients to lymphedema treatment centers and professionals, provide patient education online and by phone and provide a newsletter.

#### **OSTOMIES**

United Ostomy Associations of America, Inc.

Website: <http://www.uoa.org>

Phone: (800) 826-0826

The United Ostomy Associations of America offer many chapters around the country that provide education and support groups. These organizations make referrals to enterostomal nurses (experts in ostomies) and to distributors of ostomy equipment.

#### **FEEDING TUBES**

Oley Foundation

Website: <https://oley.org/>

Phone: 518-262-5079

The Oley Foundation is a national, non-profit organization dedicated to donating tube-feeding supplies, providing educational and emotional support, outreach, and clinical outcome information for individuals who depend on home intravenous (parenteral) and tube (enteral) nutrition, their families, professionals, and others.

## SUPPORT FOR SPECIFIC CANCERS

**Please note:** Many of the organizations listed above have excellent information and support resources around many specific cancers. The organizations below have chosen to focus on particular cancers to support with patient education, research funding and other services. These organizations provide a wide variety of services, some of which are listed below. If you contact these organizations, be sure to ask for a full listing of the services and products they offer.

### Brain Cancer

#### American Brain Tumor Association

Website: <http://www.abta.org>

Phone: (800) 886-2282

This organization provides referrals to community resources for people with brain cancer, a pen pal program, newsletter and education publications.

#### National Brain Tumor Society

Website: <http://braintumor.org>

Phone: (617) 924-9997

Volunteers at this organization provide information on treatment by phone or mail and referrals to support groups. The National Brain Tumor Society also has a newsletter and education publications.

### Breast Cancer

#### Reach To Recovery/American Cancer Society

Website: <http://www.cancer.org>

The American Cancer Society Reach To Recovery program matches trained volunteer breast cancer survivors to people living with breast cancer.

#### Susan G. Komen Breast Cancer Foundation

Website: <https://www5.komen.org>

Phone: (877) 465-6636 (GO KOMEN)

This organization offers information about breast health, breast cancer research and has a "helpline" staffed by volunteers.

#### Dr. Susan Love Research Foundation

Website: <https://www.dr.susanloveresearch.org>

This website was created by Dr. Susan Love to offer breast

cancer patients online chats with cancer experts, in-depth information and other support features. Dr. Love has written, "Dr. Susan Love's Breast Book."

### Gynecologic Cancers

#### Foundation for Women's Cancer

Website: [www.foundationforwomenscancer.org](http://www.foundationforwomenscancer.org)

There is full text education on this foundation's website about gynecologic cancers (ovarian, endometrial, uterine and cervical), including disease information, survivor stories and a guide to support organizations. The website has compiled a reading list, as well.

#### National Ovarian Cancer Coalition

Website: <http://www.ovarian.org>

Phone: 888-682-7426 (OVARIAN)

This coalition offers a newsletter, referrals to gynecologic oncologists, database searches for educational materials, chats with fellow survivors and support groups in many states or references to other organizations and ovarian cancer support groups.

### Head, Neck and Oral Cancer

#### Support for People with Oral and Head and Neck Cancer

Website: <http://www.spohncc.org>

Phone: (800) 377-0928

This group offers a newsletter with information on clinical trials, treatments, employment issues and oral care.

### Kidney Cancer

#### Kidney Cancer Association

Website: <https://www.kidneycancer.org>

Phone: (800) 850-9132

The Kidney Cancer Association offers referrals to specialists, assistance in getting insurance to cover experimental treatments, clinical trials information, online chat groups and educational publications.

### Leukemia, Lymphoma and Myeloma

#### International Myeloma Foundation

Website: <http://www.myeloma.org>

Phone: (800) 452-2873 (CURE)

This organization connects survivors to current patients and their families as well as offers education publications and a newsletter.

**Leukemia and Lymphoma Society (LLS)**

Website: <http://www.lls.org>

Phone: (800) 955-4572

The Leukemia and Lymphoma Society (LLS) is the largest voluntary health organization dedicated to funding research, finding cures and ensuring access to treatments for blood cancer patients. LLS funds lifesaving blood cancer research around the world and provides free information and support services.

**Lymphoma Research Foundation**

Website: <http://www.lymphoma.org>

Phone: (212) 349-2910 or (800) 500-9976 (help line)

This foundation funds research, has patient education materials, sponsors a nationwide buddy program partnering the newly diagnosed with lymphoma survivors, and maintains a help line with information on treatment options and clinical trials.

**Lung Cancer****Go2 Foundation for Lung Cancer**

Website: [www.go2foundation.org](http://www.go2foundation.org)

General Questions: (202) 463-2080

Helpline: (800) 298-2436

Founded by patients and survivors, GO2 Foundation for Lung Cancer, transforms survivorship as the world's leading organization dedicated to saving, extending, and improving the lives of those vulnerable, at risk, and diagnosed with lung cancer.

**LungCancer.org:**

Website: <https://www.lungcancer.org>

Phone: (800) 813-HOPE (4673)

This organization is focused on offering the latest online news in screening, detection and treatment for lung cancer. Experts answer questions; a newsletter and resource library are offered. The website is sponsored by CancerCare® and the Oncology Nursing Society.

**Prostate Cancer****Urology Care Foundation**

Website: <http://www.urologyhealth.org>

Phone: (800) 828-7866

The Urology Care Foundation's mission is the prevention and cure of urologic diseases through the expansion of

research, education and public awareness. For prostate cancer patients, this organization links together survivors, families and friends through prostate cancer support groups as well as coordinates prostate cancer awareness and advocacy programs, focusing on the issues of prostate cancer survivors.

**Us TOO**

Website: <http://www.ustoo.org>

Phone: (800) 808-7866

This organization offers many chapters that provide support groups and services to men with prostate cancer and their loved ones.

**Skin Cancer/Melanoma****Melanoma Research Foundation**

Website: <https://www.melanoma.org/>

Phone: (800) 673-1290

This foundation supports research into finding a cure for melanoma. The organization offers a newsletter.

**Skin Cancer Foundation**

Website: <http://www.skincancer.org>

Phone: (212) 725-5176

The Skin Cancer Foundation is focused on public professional education programs and offers research support.

**CAREGIVER SUPPORT****Caregiver Action Network (CAN)**

Website: <http://www.caregiveraction.org>

Phone: (855) 227-3640

The Caregiver Action Network (CAN) is the nation's leading family caregiver organization working to improve the quality of life for the more than 65 million Americans who care for loved ones with chronic conditions, disabilities, diseases and the frailties of old age. CAN serves a broad spectrum of family caregivers and is a non-profit organization providing education, peer support and resources to family caregivers across the country free of charge.



**Well Spouse Association**

Website: <http://wellspouse.org>

Phone: (732) 577-8899

The Well Spouse Association advocates for and addresses the needs of individuals caring for a chronically ill and/or disabled spouse or partner. This organization offers peer-to-peer support and educates healthcare professionals and the general public about the special challenges and unique issues “well” spouses face each day.

## EDUCATION RESOURCES

**A Quick Guide to the Health Insurance Marketplace:**

[www.healthcare.gov/quick-guide/one-page-guide-to-the-marketplace](http://www.healthcare.gov/quick-guide/one-page-guide-to-the-marketplace)

**Cancer.Net**

Website: <https://www.cancer.net/>

Phone: (888) 651-3038

Cancer.Net is a patient education website from the American Society of Clinical Oncology that provides information on more than 50 types of cancer and their treatments, clinical trials, side effects and coping. This website also includes live chats, message boards and links to support groups.

**OncoLink**

Website: <https://www.oncolink.org>

Phone: (215) 349-8895

OncoLink is a website managed by the Abramson Cancer Center of the University of Pennsylvania that provides a wide range of cancer-related information. On the website, you can find information on clinical trials, reimbursement assistance programs and a caregiver education course.

## EMOTIONAL SUPPORT

**4th Angel Patient and Caregiver Mentoring Program**

Website: <http://4thangel.org>

Phone: (866) 520-3197

The 4th Angel Mentoring Program offers free, one-on-one, confidential outreach and support from someone who has successfully made the same journey toward recovery. This program is telephone-based, so you can be connected with mentors anywhere in the world. On this website, you can request a mentor, become a mentor or receive caregiver mentoring.

**American Cancer Fund**

Website: <https://www.americancancerfund.org>

Phone: (908) 431-9800

The American Cancer Fund is dedicated to the education, support and empowerment of those diagnosed with cancer by organizing and clarifying information. This organization provides information about topics, such as: living with cancer, clinical trials, complementary and alternative medicines as well as nutrition and exercise.

**Cancer Support Community**

Website: <https://www.cancersupportcommunity.org>

Helpline: (888) 793-9355

The Cancer Support Community is an international non-profit dedicated to providing support, education and hope to people affected by cancer. This organization offers a menu of personalized services and education for all people affected by cancer.

**Caregiver Media Group**

Website: <https://caregiver.com>

Phone: (800) 829-2734

The Caregiver Media Group provides an online newsletter, workshops, audiotapes and information on caregivers and the workforce, caregiver tips and other topics.

**First Descents**

Website: <https://firstdescents.org>

Phone: (303) 945-2490

First Descents offers young adult cancer fighters and survivors a free outdoor adventure experience designed to empower them to climb, paddle and surf beyond their diagnosis, defy their cancer, reclaim their lives and connect with others doing the same. There also is a program available for cancer fighters and survivors between the ages of 40-49. Meals, accommodations and program activities are provided free of charge, and travel scholarships are available for those unable to pay travel expenses.

**Imerman Angels**

Website: <https://imermanangels.org/>

Phone: (866) 463-7626 (IMERMAN)

Imerman Angels provides personal connections that enable one-on-one support among cancer fighters, survivors and caregivers. The mentors at Imerman Angels are the same age, gender and have experienced the same type of cancer as the survivor they are paired with. This service is provided free to anyone who has been touched by cancer.



**LiveStrong Foundation**

Website: <https://www.livestrong.org>

Phone: (855) 220-7777

The LiveStrong Foundation provides support for individuals affected by cancer. The foundation offers online and phone support as well as informational resources, such as articles, videos, information about insurance challenges, planning medical care, caregiver support and information on other topics related to dealing with cancer.

**Women Survivors Alliance**

Website: <https://www.womensurvivorsalliance.org>

The mission of the Women Survivors Alliance is to establish a network where women affected by cancer can find their voice, improve their quality of life and embrace telling their stories.

## RESOURCES FOR YOUNG ADULTS

**The Cassie Hines Shoes Cancer Foundation**

Website: <https://www.cassiehinesshoescancer.org/>

Phone: (586) 322-0991

The mission of the Cassie Hines Shoes Cancer Foundation is to help young adults battling cancer by providing them resources, social support programs and more in order to enable them to live life beyond cancer. Some of the resources available through this foundation include financial assistance for those who qualify, legal help, caregiver resources and general information related to fighting cancer.

**Group Loop**

Website: [grouploop.org](http://grouploop.org)

Group Loop is a free and safe online community where teenagers affected by cancer can meet and connect with one another to build social and emotional support as well as regain a sense of control over their lives. Group Loop also provides educational information about cancer and tools to cope with the anticipated changes in relationships and day-to-day activities due to a cancer diagnosis.

**Hope for Young Adults with Cancer**

Website: <http://www.hope4yawc.org/>

The mission of Hope for Young Adults with Cancer is to connect these individuals with their peers in the fight to provide direct financial support. This organization also provides a social network and outlet for young adults between the ages of 18 and 40 who are battling, surviving and living with cancer.

**Missouri Courses Access + Virtual School Program (MOCAP)**

Website: <https://mocap.mo.org/>

Phone: (573) 751-2453

The Missouri Virtual Instruction Program (MoVIP) offers online courses to Missouri students in grades K-12. MoVIP is a tuition program offering courses to public, private and homeschool students. The program is state-funded and can accommodate a limited number of students, who, for medical reasons or special activities, may not be able to attend their local schools in person.

**The Ulman Cancer Fund for Young Adults**

Website: <http://ulmanfund.org/>

Phone: (410) 964-0202

The Ulman Cancer Fund for Young Adults works to support, educate, connect and empower young adult cancer survivors.

## LOCAL COMMUNITY RESOURCES

**Food Assistance**

Apply for Food Stamp assistance at the local Division of Family Services.

**Meals on Wheels:** Homebound elderly are delivered lunch.

Rolla	341-2929
St. James	265-7072
Licking	674-3104
Waynesville	774-2668
Vienna	422-3834
Salem	729-2793
Cuba	885-2909
Crocker	736-5405
Bourbon	732-4268
Owensville	437-3096

## Hospice

Hospice organizations offer comfort measures to patients who have been given a prognosis of 6 months or less and who have stopped aggressive treatment. Homecare, respite care, pain control, counseling and other services are provided.

**Phelps Health - Rolla:** (573) 364-2425

**Alternative Hospice - Cuba:** (573) 885-7816

**BJC Hospice - Sullivan:** (573) 468-3630

**Heartland Hospice - Washington:** (636) 390-4723

**Hospice & Palliative Care Compassus – Jefferson City:** (573) 556-3547; additional offices in Lebanon, Osage Beach, Mountain Grove and West Plains

**Hospice of Care - Houston:** (417) 967-1279

**Integrity Hospice - Lebanon:** (855) 442-4968

**Mercy Hospice – Washington:** (636) 239-7128

**Preferred Hospice - Rolla:** (573) 426-6751; additional offices in Columbia, Ozark and Farmington

**Regional Hospice - Lebanon:** (417) 532-5139

**Three Rivers Hospice - Licking:** (573) 674-1127

## Home Healthcare

**Phelps Health Homecare:** Rolla — (573) 364-2425

**Auxi/Missouri Home Health:** Rolla — (573) 341-3456

**BJC Home Care Services:** Sullivan — (573) 468-5167

**Home Health of the Ozarks:** Houston — (417) 967-1240

**Lake Ozark Home Health:** Crocker — (800) 481-2219

## Long-Term Care

**Nursing Home Compare:**

[www.medicare.gov/NHCompare/home.asp](http://www.medicare.gov/NHCompare/home.asp)

A guide to help select a nursing home in your area. This gives detailed information regarding the state surveys conducted in the facilities.

## Medicaid Offices

**Crawford County Division of Family Services:**

Steeleville — (573) 775-2146

**Dent County Division of Family Services:**

Salem — (573) 729-4137

**Maries County Division of Family Services:**

Vienna — (573) 422-3114

**Phelps County Division of Family Services:**

(573) 368-2340

**Pulaski County Division of Family Services:**

(573) 774-6121

**Med Assist for Phelps Health patient assistance with Medicaid application:** (573) 458-7719

## Rent Assistance

**Meramec Regional Planning Commission, HUD:**

(573) 265-2993

**Rolla Housing Authority, housing within Rolla city limits:**

(573) 364-6460

## Social Security Administration Office

1813 East 10th Street, Rolla, MO 65401 • (800) 551-2056

## Financial Assistance

**Grace**

601 N Elm St

Rolla, MO 65401

573-368-5577

GRACE screens, coordinates, and refers families to community service organizations and provides direct assistance as resources permit. We work closely with our other organizations in the area to maximize efforts to help each client and reduce duplication of services. We financially assist clients with rent, electric, medications, heat, air conditioning, and gas. We also assist in unusual circumstances as they arise on a case by case basis.

**Salvation Army**

102 E. 4th St.

Rolla, MO 65401

573-368-4919

The Salvation Army offers financial assistance with utility bills, rent, and medications.

## SUPPORT GROUPS AT PHELPS HEALTH

At the Delbert Day Cancer Institute, we recognize the importance of cancer support groups and have a variety of options for our patients and survivors. Please contact the nurse navigator at (573) 458-7164 for current support group schedules.

### Define Your Shine

Phone: (573) 458-3324

Through Define Your Shine, women in cancer treatment learn techniques to restore their self-image and cope with appearance-related side effects.

Certified beauty professionals provide tips on makeup, skin care, nail care and head coverings.

This

program is sponsored by Phelps Health.

### Diabetes Support Group

**Time:** 10:00 AM - Noon

**Dates:** First Saturday of the month, no classes in January, July or September

**Location:** Private Dining Room 2, Phelps Health

**Contact:** (573) 458-7697

**Course:** The diabetes support group forms a bridge between formal healthcare and individual self-management. By gathering people with common concerns, goals and interests, members feel less isolated.

### Grief Recovery Support Group:

**Contact:** Phil Cox at (573) 458-7935

**Course:** This support group is an eight-week action program for moving beyond death, divorce and other losses. People say you have to let go and move on in your life, but they do not tell you what you need to do to accomplish that. The Grief Recovery Method® Grief Support Group not only makes that possible but provides partnerships and guidance to ensure that it happens.

## AREA SUPPORT GROUPS

### Cancer Support Group in Vienna

A support group for patients with all types of cancers is held Tuesdays at 6:30 PM at Visitation Catholic Church, across the street from the school in Vienna, Missouri.

### Project WIN - Cancer Support Group

Winners' Circle meets each Thursday at 6:00pm at the Lifeway Center, 701 Main Street (North Highway 19) in Salem, Missouri. Contact Patty Powell at (573) 729-2481 or Sheri Stack at (573) 247-1367.

## TRANSPORTATION SERVICES

### Local Transportation Services

Medicaid Transportation: (888) 863-9513

SMTS: Rolla (573) 364-7687

Salem (573) 729-3133

Steelville (573) 775-2793

Phelps Health: (573) 341-8278

### Taxis and Other Private Transportation Services

American Cab (573) 364-6021

City Cab (573) 341-3733

Salem Taxi (573) 729-4500

At Your Service (573) 364-7863

Show Me Cab (573) 336-4455

### Long-Distance Transportation

**Air Charity Network** offers air travel to treatment centers for cancer patients and their caregivers.

Website: <http://aircharitynetwork.org/>

Phone: (877) 621-7177

**Corporate Angel Network** uses empty seats on corporate aircraft to help cancer patients reach treatment centers.

Website: <http://corpangelnetwork.org>

Phone: (914) 328-1313

**Lifeline Pilots** offers air travel to treatment centers for cancer patients and their caregivers.

Website: <https://lifelinepilots.org/>

Phone: (800) 822-7972

**Mercy Medical Angels** offers air travel to treatment centers for cancer patients and their caregivers.

Website: <http://mercymedical.org>

Phone: (757) 318-9174

**Raquel's Wings for Life** uses empty seats on corporate aircraft to help cancer patients reach treatment centers.

Website: <https://raquelswingsforlife.com/>

Phone: (940) 393-2999

## UTILITY ASSISTANCE

**LIHEAP (Low Income Home Energy Assistance Program):**

This program helps families pay their utility and heating bills and get emergency services, such as blankets, emergency lodging, furnace and central air replacement or repair, window air conditioning units and wood stoves. For more information, call (855) 373-4636 or visit <https://dss.mo.gov/fsd/energy-assistance/index.htm>.

## LOCAL AGENCIES

**MOCA (Missouri Ozarks Community Action):** Covering Camden, Crawford, Gasconade, Laclede, Maries, Miller, Phelps and Pulaski counties

306 South Pine Street  
Richland, MO 65556  
(573) 765-3263

**Intercounty Electric Cooperative Association:** The Operation Round-Up programs helps local, low-income and disabled individuals and families within the Intercounty Electric service territory. The funds can be used to pay for personal and home needs. For assistance, call (866) 621-3679.

**Laclede Electric Cooperative:** The Operation Round-Up programs helps local, low-income and disabled individuals and families within the Laclede Electric service territory. The funds can be used to pay for personal and home needs. For assistance, call (417) 532-3164, extension 2234.

**Crawford Electric Cooperative:** The Operation Round-Up programs helps low-income and disabled individuals and families within the Crawford Electric service territory. The funds can be used to pay for food, shelter, rent, clothing, prescriptions and healthcare needs for needy individuals. For assistance, call (800) 677-2667.

**G-Ma Pam's Rack Pack:** This local agency can assist cancer patients with financial needs who are undergoing treatment and live within the Licking School District.

**Project WIN:** This local agency can assist cancer patients with financial needs who are undergoing treatment and live in Dent County. For assistance, call Sheri Stack at (573) 247-1367.

**Ya Yas:** This local agency can assist cancer patients living in the Belle area with financial issues. For assistance, call (573) 308-9505.

**Gateway to Hope:** This agency in St. Louis can help uninsured or low-income women diagnosed with breast cancer who are living in Missouri. This organization can help coordinate medical treatment and assist with financial needs. For assistance, call (314) 569-1113.

## VETERANS ADMINISTRATION

### Hospitals

VA Columbia (573) 814-6000

VA St. Louis (314) 652-4100

### Clinics

Waynesville (573) 774-2285

St. James (573) 265-0448

## WIG FITTINGS

Wig fittings are available at the Delbert Day Cancer Institute. Contact (573) 458-7164 for more information.

## BRA FITTINGS

### Sinks Pharmacy South

Bra fittings are available at Sinks Pharmacy South and can be arranged through the Delbert Day cancer Institute.

## NOTES

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## NOTES

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Phelps Health complies with applicable federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability or sex.

ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 1-573-458-7684, 1-573-458-7922.

注意：如果您使用繁體中文，您可以免費獲得語言援助服務。請致電1-573-458-7684, 1-573-458-7922。



## IMPORTANT INFORMATION AT A GLANCE

## Emergency Contacts:

Name: \_\_\_\_\_ Phone Number: \_\_\_\_\_

Name: \_\_\_\_\_ Phone Number: \_\_\_\_\_

Primary Care Doctor:

Name: \_\_\_\_\_ Phone Number: \_\_\_\_\_

Nurse/Contact Person: \_\_\_\_\_

### Other Doctors:

Name: \_\_\_\_\_ Specialty: \_\_\_\_\_

Phone Number: \_\_\_\_\_ Contact Person: \_\_\_\_\_

Name: \_\_\_\_\_ Specialty: \_\_\_\_\_

Phone Number: \_\_\_\_\_ Contact Person: \_\_\_\_\_

Name: \_\_\_\_\_ Specialty: \_\_\_\_\_

Phone Number: \_\_\_\_\_ Contact Person: \_\_\_\_\_

Name: \_\_\_\_\_ Specialty: \_\_\_\_\_

Phone Number: \_\_\_\_\_ Contact Person: \_\_\_\_\_

## DATES TO REMEMBER

[illegible]

## MEDICATIONS

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**YOUR QUESTIONS**

Appointment With: \_\_\_\_\_ Date: \_\_\_\_\_

Questions: \_\_\_\_\_

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